

**The Learning Disability Knowledge Questionnaire (LDKQ) and Information Manual:
The Development of a Staff Training Tool for Use with Social Care Workers**

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DECLARATION

This thesis has been composed by myself and the work contained herein is my own.

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ABSTRACT

Knowledge and understanding of the defining features and facts about a learning disability is often assumed among social care staff working with this client group but it is rarely investigated. The literature suggests that social care staff have a paucity of knowledge relating to the client group with which they work. At present there is no accepted objective measure of knowledge of a learning disability in social care staff. This study presents the Learning Disability Knowledge Questionnaire (LDKQ) and accompanying information manual focusing on the pertinent facts and defining features relating to a learning disability. A 30-item questionnaire was developed and a trial of the questionnaire was completed by social care staff (n=92), working in residential and day care services for adults with a learning disability. The questionnaire was analysed for internal consistency reliability, test-retest reliability and sensitivity to identifying different levels of knowledge. A general population sample (n=35) with no experience of working with adults with a learning disability completed the questionnaire. A sample of social care staff (n=32) took part in the training session, completing the LDKQ before and after the presentation of the information manual and at one-month follow up. Levels of knowledge were compared. The results are discussed with reference to related literature and suggestions are made for further work.

INTRODUCTION

*I hear and I forget,
I see and I remember,
I do and I understand'*

1.1 Acquiring knowledge

This old Chinese proverb encapsulates the process of human learning. Human learning is not a simple concept and the ability of humans to acquire knowledge and learn information has been the focus of decades of research. Essentially learning is a hypothetical construct that is inferred through the assessment of behaviour, as it is not possible to measure it directly (Gross, 1999). Learning has been defined as, '*a relatively permanent change in behaviour due to past experience*' (Coon, 1983) or alternatively, '*the process by which relatively permanent changes occur in behavioural potential as the result of an experience*' (Anderson, 1995). The inclusion of the term 'behavioural potential' in the definition refers to the fact that learning is assessed through performance and although learning is assumed to be permanent, performance can be variable e.g. because of fatigue or emotion and so true potential may not be accurately assessed.

To maximise the acquisition of new material in an individual, it is important to understand the processes and factors influencing the acquisition and retention of information. With this in mind, it is possible to choose the most appropriate format

to convey information and work out the best way to assess changes in knowledge that can be attributed to the experience of training.

1.2 Training

1.2.1 Methods of Training

In the literature, a variety of procedures have been employed, used alone or in combination generally to increase the effectiveness of interactions between staff and clients. Buckley and Caple (1995) describe the various methods used in training.

Firstly, instructional procedures consist of lectures and written or verbal information and have very little audience participation. Lectures are a useful way of covering a lot of information but are not useful for teaching skills or treatment procedures (e.g. Cullen, 1988) and risk losing the attention of the audience due to lack of interaction. Richman et al. (1988) adopted a didactic approach and found that there was limited implementation of programs and activities after training. Didactic approaches most often result in increases in verbal knowledge regarding procedures, without concurrent increases in therapeutic competence in the same areas (Jahr, 1998). Mørch (1990) found a low correspondence between the practical application of therapeutic techniques and verbal competence. Despite these findings, instructional procedures often form part of training packages. It is not known whether they increase effectiveness of accompanying procedures.

Secondly, demonstrations consist of a 'live performance' of a skill or procedure and tap into the process of behaviour modelling. Modelling has proved effective in direct work with people with a learning disability (McClannahan and Krantz, 1993). It is a good way of showing the relationship between activities but can be time consuming.

Thirdly, lessons are used mainly to teach skills and facts. Lessons encourage interaction in the form of question and answer sections, practice and feedback. They have the advantage of being flexible, unlike lectures and can adapt to the audience in terms of content and pace of presentation (Buckley and Caple, 1995). Lessons are a useful way of assessing performance.

Other techniques include role-play which may be useful in teaching application of the procedures in analogue situations (Gardner, 1972) and modelling. Modelling is typically used as one component of training (e.g. Koegel et al., 1978; Koegel et al., 1977). Buckley and Caple (1995) comment that discussions are used as a way of investigating attitudes, ideas and solutions to problems. Discussion is normally used in conjunction with other methods and used to reinforce key points. It can be a useful way of finding out a person's view, experience and knowledge but can be time consuming and potentially a waste of time if people opt out (Buckley and Caple, 1995). Finally, Buckley and Caple (1995) state that learning packages allow people to study topics in greater depth as they typically consist of a collection of reading material, videos or case studies. The pace of learning is flexible and the most appropriate topic can be selected.

Feedback on staff behaviour has become a common component in staff training and usually takes the form of an evaluation. It is aimed at improving an individual's performance and is presented in either written or verbal format (Schinke and Wong, 1977; Parsons et al., 1987; Green et al., 1991; Harchik et al., 1992; Gross et al., 1994). Feedback can be given immediately or after a period of weeks following training (e.g. Koegel et al., 1977; Parsons et al., 1987; Alavosius and Sulzer-Azaroff, 1990). Jahr (1998) suggests that feedback is difficult to evaluate as an effective procedure for changing staff behaviour because of the variations in format, timing and unambiguous definition.

Skill based measures involve *in vivo* observation of staff skills before and after training in naturally occurring environments. This has been termed 'ecological assessment' (Farrell, 1982; Milne, 1985; Landesman-Dwyer & Knowles, 1987) and includes a follow up aimed at evaluating the maintenance of skills after training (Milne, 1986). *In vivo* skills assessment is time-consuming so simulated performance have been used as an alternative. Staff watch scenarios on videotape and make comments on how they would approach the situation (Milne, 1981). This technique is useful but Binney (1992) comments that the best measure of staff proficiency is an improvement in the client group.

Typically, staff training will consist of combinations of the above techniques. Combinations of procedures are thought to be more effective than using one in isolation (Koegel et al., 1978; Kazdin, 1988).

1.2.2 Factors Affecting Training

‘Training’ is a term that has been applied to the transfer of areas of knowledge, skills and attitudes. The format and structure of training sessions will be partly dictated by the kind of material to be covered. Buckley and Caple (1995) suggest that the training objective should be considered when choosing which learning principles and conditions to employ in training. The current models of learning and memory have shaped the way in which conditions of learning have been selected to facilitate learning and retention of information. A meaningful context, rehearsal and spaced practice are factors that are understood to encourage the acquisition of knowledge. Figure 1 contains the appropriate conditions for increasing knowledge of a particular area in a target population (Buckley & Caple, 1995).

As well as the type of material to be presented, the characteristics of the staff group must be taken in to account. Buckley and Caple (1995) review a number of factors that should be considered when planning to train a group of staff. Firstly, the age of the participants is important as memory and time taken to process information is known to decline with age. This may mean that information is presented at a slower pace and in a greater variety of ways e.g. visually as well as verbally.

Secondly, levels of intelligence and ability of participants influence the way in which information should be conveyed. For example, people of lower levels of ability learn best when training is cumulative rather than massed and some staff may be less familiar with training and reticent about becoming involved (Binney, 1992) so

shorter, regular sessions that build on each other would be better. It is also better for sessions to be structured, guided and concrete as oppose to unstructured (Stammers & Patrick, 1975).

Figure 1: Matching training objective with conditions for learning

Training Objective	Conditions for Learning
<i>Knowledge</i>	
Comprehension	Meaningful context Verbal introduction Feedback and rehearsal Reflection Spaced practice
Learning and retention	Meaningful context Immediate and accurate feedback Prompting Rehearsal Spaced practice

The literature suggests (Binney, 1992) that ‘ground work’ may need to be done to engage some staff in the process of training, such as improving attitudes towards the material in question. It cannot be assumed that a blanket approach to training staff of differing levels of qualification will be effective. Training may need to be tailored

and aimed at what Vygotsky termed the 'zone of proximal development' (Vygotsky, 1978) of participants. Vygotsky proposed a developmental theory grounded in the belief that cognitive development is the result of a social process involving human interactions. His view of 'children as apprentices' suggests the notion of them moving from being able to do things with the help of others, to doing things independently. Vygotsky focused on the collaborative nature of development whereby adults or more experienced peers provide a 'scaffolding' or context for a child to start to build competency and do more and more independently.

'The zone of proximal development defines those functions that have not yet matured but are in the process of maturation, functions that will mature tomorrow but are currently in their embryonic state. These functions could be termed the 'buds' or 'flowers of development' rather than the 'fruits' of development. The actual developmental level characterises mental development retrospectively, while the zone of proximal development characterises mental development prospectively'.

(Vygotsky, 1978)

Although this theory relates to the cognitive development of children, it is possible to relate the principle to the training of adults. This principle implies that staff training should be pitched at a level and in a way that can be understood by its participants. The structure, guidance and context for development can be provided by appropriate training, enabling participants to develop their own understanding.

Sperlinger (1989) stresses that staff training must relate to the demands of the job and the skills required of staff within the place they work. This view is supported by Fitzsimmons and Barr (1997) who warn that training input must allow for the context within which staff work and their existing knowledge and beliefs. There is no point

in providing information that is not valued or expected of them, in fact training should *'provide opportunities for learning to be a change agent in one's own work setting'* (Mittler, 1987). In a similar vein, Binney (1992) comments that the skills identified as valuable and included in training may not be those that are highly valued in staff groups who have other priorities. This highlights the issue of attrition of skills in qualified staff and the need for ongoing training in basic knowledge and skills.

1.2.3 The Effectiveness of Training

There is scepticism about the impact that staff training has on positively influencing staff behaviour and practices toward clients. Mittler (1987) comments that:

'A naïve faith in more and better training...now being tempered by a growing realisation that courses do not necessarily lead to change in the behaviour of participants, far less changes in the client with whom they work'.

(Mittler, 1987)

Subsequent research studies appear to partly support this perception. Smith et al. (1992) conducted two studies designed to assess the acquisition and generalisation of skills acquired in workshops to group homes. A sample of staff took part in a week of workshops concentrating on the teaching of behavioural principles and treatment techniques in relation to people with learning disabilities. The results showed that there was an increase in treatment skills compared with a control group.

The second study consisted of pre and post observations of clients in the group homes where the staff worked. There was no evidence that the workshops had an effect on group home functioning. Clients did not spend more time with or interacting with caregivers and did not spend less time in self-stimulatory activities which might be expected if the staff had taken on board the training. The authors conclude that there was an unsatisfactory generalisation of behavioural principles and techniques. This is consistent with other research that there is little evidence of generalisation of skills to the workplace, even though staff improve as a result of training (Ziarnick & Berstein, 1982).

It was suggested that despite receiving training in behavioural principles, the generalisation of the skills learned might be inhibited by the low level of theoretical knowledge in the trained group. They may have had difficulty in identifying situations in which skills could be applied. The importance of theoretical knowledge was emphasised by Koegel et al. (1978).

The transfer of training is effected by two factors, *physical* and *psychological fidelity* (Baldwin & Ford, 1988). Firstly, the extents to which conditions are similar to a person's work (physical fidelity). Secondly, the degree to which a person finds similar meaning to what is provided in training and what is evident at work (psychological fidelity). In order to promote these factors, it might be more productive to train staff at their workplace or provide additional consultation at the workplace following training.

The literature so far presents a less than optimistic view of the impact staff training and poses the question of how to improve outcomes and what factors are important in evaluating the component parts of training as a way of teasing out effectiveness.

1.2.4 Evaluation of training

In general, there has been a lack of evaluation of training aimed at behaviour change agents (Knowles & Landesman-Dwyer, 1986). Staff training must consider the purpose, content and evaluation of the information presented. Van Gelder et al. (1996) recommends that multiple levels of outcome be evaluated as appropriate in order to determine whether it has been of use to participants. For example, learner reactions, acquisition of skills and knowledge, job application and organisational impact (Kirkpatrick, 1967; Shelton & Alliger, 1993).

The American Association of Behaviour Therapists' continuing education committee (Heinrich, 1981) recommended a variety of levels of training evaluation, ranging from a training needs assessment of the target group, to trainee satisfaction, knowledge, skill acquisition and utilisation through to outcomes with client groups. It is recommended that as a minimum, measures of knowledge and skills should be included in the evaluation of training (Wright et al., 1987).

For example, Binney (1992) devised a skills based workshop aimed at equipping staff to participate effectively in activity groups. In this study, the measures used included a measure of attitude to stimulation activities for people with profound

learning disability, a measure of knowledge and a simulated performance using video clips and multiple choice answers. Two of the video clips pertained to the selection of appropriate materials for clients of different levels of ability. The rest related to a choice of the skill needed by staff to stimulate activity or exploration in the situation. Some clips showed staff using the correct skills, whilst others showed them using inappropriate behaviour. The underlying idea being that stimulation is matched to a client's current level of functioning.

Pre and post training assessments were taken to provide information on which factors were relevant to the effectiveness of training and how it could be improved. The evaluation of training can provide information about the training needs of different staff groups and factors that may influence the effectiveness of subsequent training.

1.3 Questionnaires and Questionnaire Design

One of the most commonly used ways of assessing an individual's knowledge in a given area is to administer a questionnaire. Questionnaires have been used effectively in different fields of work for a number of reasons. Firstly to identify misconceptions (Antonak et al., 1989) and gaps in knowledge (Sarvela et al., 1990; Jarvie et al., 1993), which would indicate the need for educational training. Secondly they have been used as a teaching tool to assist with in-service training (Sarvela et al., 1990; Sterrick & Foley, 1999) and thirdly as a way of measuring the effectiveness and durability of training (Sarvela et al., 1990).

Elland and Rogers (1993) provided a concise guide to the effective construction of questionnaires. This guide to questionnaire design recommends that the vocabulary used in items should be matched to the vocabulary of the respondents. There should be a 40-60% 'true or agree' keyed items and items should be piloted before data collection. Questions should not contain 'no' or 'not' words and should not contain double-barrelled items. Questions using 'un', complex grammatical forms, irrelevant items and loaded questions should be avoided. They recommend that response formats should be uniform throughout the questionnaire and non-committal responses are best avoided.

The following sections contain examples of studies employing questionnaires for a variety of purposes. The purpose, design and process of validation of the questionnaires are summarised.

1.3.1 Identifying Misconceptions

In 1926, the National Committee for Mental Hygiene, Inc., published a pamphlet titled 'About Feeble-mindedness' intended for distribution to the general public. The pamphlet included nine statements about 'what some people believe', countered by nine statements entitled 'what science teaches today'. The source of the information is not known but is presumed to reflect misconceptions and scientific thoughts of the time. Thirty years later, Winthrop and Taylor (1957) investigated whether these misconceptions were still prevalent. However, they were not able to directly

compare the data, as the corresponding percentages were not available from the earlier study.

In 1989 Antonak et al. compared current misconceptions regarding 'mental retardation' with those in 1956, using an updated version of the nine item questionnaire developed by Winthrop and Taylor (1956). The results found that factors related to an accurate perception of mental retardation included: the presence of greater occupational, personal life and socialisation experiences with people with learning disability. People who had more direct contact with people with learning disability expressed fewer misconceptions. The least educated respondents were not aware of the environmental causes of learning disability and fewer people confused mental retardation with mental illness in 1986 than 1956.

1.3.2 Identification of Levels of Knowledge

Sarvela et al. (1990) devised a tool to be used as a component of a communication disorders training for workers in a geriatric care setting. Sarvela et al. were aware that communication disorders are a major health problem in older people but few health care workers have specific training on the identification, needs and treatment of people with communication difficulties. The aim was to use it as a needs assessment instrument, a training tool and as a way of evaluating the effectiveness of the training.

The development of the questionnaire involved initially a collection of a pool of 38 items, which were piloted with a group of staff. The items were analysed and a reliability estimate for each item was calculated. Unreliable items were deleted and a panel of experts in the field assessed content validity. The final form was produced which aimed to test general knowledge about communication disorders in geriatric care workers.

The questionnaire was given to 208 workers and then analysed using descriptive statistics, item analysis, tests of reliability (Cronbach' alpha) and validity (content, construct) and principle components analysis.

The instrument was found to be reliable and valid and useful for identifying the need for staff education. Sarvela et al. suggests a number of formats that training could take, including using the data to decide on goals and targets and ways of achieving these objectives. The baseline data could be used as way of evaluating the effectiveness of the training. Secondly, it could be used for in-service training. In this format, staff could complete the questionnaire and then spend up to an hour discussing and answering questions raised by each item. Finally, the questionnaire can be used as a follow up to training and results compared with baseline data gathered at the needs assessment. This would fulfil the criteria proposed within the guidelines for clinical effectiveness and clinical governance (DoH, 1997).

The Epilepsy Knowledge Questionnaire (Jarvie et al., 1993) was devised as a tool for measuring an individuals level of knowledge about epilepsy and its effects. The

commission for the Control of Epilepsy and its Consequences (1977) highlighted the importance of patient knowledge in relation to disability. The Epilepsy Knowledge Profile-General (EKP-G) as it is known is described as a short self-administered questionnaire designed to assess the misconceptions, fears and knowledge a patient may have. It is to be used to assist in the treatment and care of people with epilepsy. It has subsequently been used in a training programme designed to increase epilepsy awareness in lay carers of people with a learning disability (Sterrick & Foley, 1999).

The development of the questionnaire involved three main stages; firstly the development of a format and item pool, secondly external validation and refinement of the item pool and finally a clinical trial. The end result proved to be a valid, reliable and sensitive measure of knowledge of epilepsy. It can be used to assess a person's general level of knowledge of epilepsy as well as providing information about their understanding of specific areas. It enables clinicians to target information and advice on areas of concern e.g. poor understanding of diagnosis and so acts as a need assessment tool.

Sterrick & Foley (1999) have incorporated the EKP-G in to a teaching protocol for lay carers on epilepsy. It is used as an introduction to the teaching to identify gaps in knowledge and myths and misconceptions regarding epilepsy before formal teaching begins.

A less structured format for assessing levels of knowledge is to use open-ended questions. McKenzie et al. (1999a, 1999b) used open ended questions to examine

levels of knowledge of learning disability in a sample of four staff groups working with people with a learning disability in different settings i.e. health, residential, day care and general practice. They simply asked, 'What is a learning disability?' and rated the responses according to DSM-IV (APA, 1994) criteria of learning disability. They found that level of knowledge of learning disability was not high in any of the groups.

McKenzie et al. (1999a) found that only two of the criteria for learning disability were identified by a quarter of respondents. Impaired intellectual functioning and impaired adaptive functioning were identified; both of which have immediate relevance to the every day functioning of an individual. Respondents identified the criterion of childhood onset least.

1.4 Training needs in the care of people with learning disability

1.4.1 Historical Developments in Service Provision

The provision of services for people with a learning disability has developed and evolved over the years from a time when people were resident in large NHS hospitals to the present day when people tend to live in the community. Social care staff have a pertinent role to play both in the social and health care of people with a learning disability as the trend towards community care continues. The introduction of the community care model can be traced back to the principle of normalisation.

Wolfensberger (1972) was a major proponent of normalisation and defined it as:

'The utilisation of the means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible'.

(Wolfensberger, 1972. In Barr, 1995)

As the focus moved away from the provision of normal services towards that of social value, the concept was renamed as 'social role valorisation' (Wolfensberger, 1983). Normalisation can be seen as a framework from which to plan and run local services in a way that allows people with a learning disability the same opportunities to develop skills, participate in the community and be treated in valued way (Barr, 1995).

The concept of normalisation acted as one of the catalysts for the eventual closure of long stay institutions and the resettlement of people who did not require specialist medical or nursing care in to smaller community care homes. Social care staff adopted the role of the day to day support of people with learning disability who had previously been cared for by health care professionals. The present role of social care staff includes supporting all aspects of a person's social, health and personal care within a framework based on normalisation. This raises the question of whether this staff group has a clear understanding of what this role entails.

Along with the principle of normalisation, further philosophies were being developed relating to service provision. In 1981 Tyne and O'Brien suggested that a good service recognised and promoted the five accomplishments i.e. choice, community presence, respect, relationships and competence (Figure 2).

Figure 2: The Five Accomplishments

The Five Service Accomplishments

1. Ensuring service users are *present in the community* by supporting their presence in neighbourhoods, schools, work places, shops, recreation facilities and churches as ordinary citizens.
2. Ensuring service users are supported in making *choices* about their lives and encouraging people to understand their situation and the options they face, act in their own interest in small matters and issues such as who to live with and what work to do.
3. Developing the *competence* of the service user by developing skills and attributes that are functional and meaningful in natural community environments and relationships (skills and attributes which significantly decrease a person's dependency or develop personal characteristics that others value).
4. Enhancing the *respect* afforded to service users by developing and maintaining a positive reputation for people who use the service by ensuring that the choice of activities, locations, forms of dress and use of language promote a perception of people as developing citizens.
5. Ensuring that service users participate in the life of the community by supporting people's natural *relationships* with family, neighbours and co-workers, widening each individual's network of personal relationships to include an increasing number of people.

(O'Brien, 1992)

It can be argued that social care workers need a clear understanding of what a learning disability is (Appendix 3) if they are going to implement the five accomplishments in relation to people with a learning disability living in the community. In addition, social care staff have a legal and moral obligation to have knowledge of the defining features, needs and characteristics of the clients in their remit.

'Persons professing skills in working with the handicapped... should be aware of the characteristics and susceptibilities of the categories of handicap with which they work'.

(Ward, 1984, pp. 57)

To be able to effectively fulfil this legal obligation staff need to understand the limitations of this client group and find a way of balancing it with the notion of 'ordinary living' and the five accomplishments (Tyne & O'Brien, 1981). In order to recognise 'duty of care' individuals need an awareness that a person with a learning disability by definition does not have the intellectual capacity or skills to make an informed choice about certain issues (McKenzie et al., 1999a). The practical difficulty of this task is borne out by research that suggests the concept of 'duty of care' is not widely understood or acted upon in practice.

McKenzie et al. (1999a) reviewed the literature relating to the concept of duty of care and found that the tolerance of antisocial and dangerous behaviour of some clients was high and incidents of theft, criminal damage and sexual assault often went unreported (Lyall et al., 1995). Other studies found that the sexual abuse of clients with a learning disability is often dealt with haphazardly because staff are unclear of

their roles and responsibilities (Brown et al., 1994; McCarthy & Thompson, 1997).

At a very basic level social care staff do not appear to appreciate what is legally expected of them.

1.4.2 Knowledge of Learning Disability in Social Care Settings

To develop an understanding of the notion of duty of care in relation to recognising and enabling individuals to access the appropriate services, staff need a greater awareness of the defining features and consequences of learning disability.

Recent studies appear to suggest that social care staff have a paucity of knowledge about learning disability. In a recent study McKenzie et al. (1999b) surveyed a sample of four staff groups working with people with a learning disability in different settings i.e. health, residential, day care and general practice. They found that level of knowledge of learning disability was not high in any of the groups and only a quarter of respondents could identify two of the criteria for learning disability. Impaired intellectual functioning and impaired adaptive functioning were identified, while childhood onset was the least identified criteria of a learning disability. They suggest that the salience of a particular criterion may be affected by the interventions the workers use. For example, behavioural techniques (LaVigna & Donnellan, 1986) or interventions based on the relationship between individuals (McGee et al., 1987) are not directly concerned with developmental aspects of learning disability. As such childhood onset is not a pertinent issue and may explain why it is not identified.

McKenzie et al. (1999a) propose that the lack of awareness of the defining features of learning disability may emanate from staff perceptions of the use of labels as stigmatising. Labelling individuals may be viewed as contrary to the notion of having an 'ordinary life' implicit in the principle of normalisation (Wolfensberger, 1972). But, as Burton (1997) commented, if a group is not defined and its limitations made explicit and understood then it will not receive the support it requires and the staff involved will be at risk of failing to fulfil their duty of care. The implementation of therapeutic approaches or care packages is made difficult if carers do not have a basic understanding of the client group with which they work (McKenzie et al., 1999a, 1999b).

A study looking at communication between staff and clients adds support to the claims made by McKenzie et al. (1999a, 1999b). McConkey et al. (1999) found that staff overly relied on verbal acts and even when the client was non-verbal they continued to use verbal questions and failed to adjust their language to the client's level of understanding. McConkey et al. (1999) suggests that staff may misjudge the communicative competence of their clients. Purcell et al. (1999) found that staff tend to overestimate the client's ability to understand language, underestimate hearing disabilities and have difficulty identifying a client's non-verbal behaviours as a means of communication. This study lends further support to the argument that staff do not have a clear understanding of their client group, which has consequences for the individual's quality of life.

McKenzie et al. (1999a, 1999b) includes a review of the literature relating to the impact of lack of knowledge among staff. They found that it could impact on morale, staff turnover and client behaviour (Allen et al., 1990; Sharrad, 1992; Hastings & Remington, 1994). Community care staff stated that one of the significant sources of stress was their difficulty in understanding the clients, which resulted in elevated levels of staff burn out and job turnover (Bromley & Emerson, 1995). This clearly has an impact on the quality of care received by clients.

McKenzie et al. (1999a, 1999b) also reviewed the studies relating lack of staff training and the impact on the lives of people with a learning disability. This review suggested that staff knowledge and experience effect job turnover, morale, attitudes, and have an impact on staff behaviour (Keshavan et al., 1991; Mørch & Eikeseth, 1992; McCabe, 1993).

1.4.3 Knowledge of Health Needs in Social Care Settings

By definition, 'duty of care' also relates to ensuring that an individual with a learning disability is given the practical, physical and emotional support needed to allow them to function in an adaptive way. People with a learning disability have needs that often extend beyond those in the general population. These needs may not have been fully acknowledged in the past but have recently been highlighted in a paper by, Espie and Brown (1998) who presented a comprehensive overview of health needs and learning disabilities. The paper highlighted that, '*there has never been a more*

important time to consider the health needs of people with learning disabilities'

(Espie & Brown, 1998).

The publication of the Health of the Nation Policy (HMSO, 1992) and the Health of the Nation Strategy for people with Learning Disabilities (DoH, 1995) have addressed health care for the general population and specific aspects of health care relating to people with learning disabilities. It is suggested by the authors that the myth that this population are generally in good health stems from the notion of wanting to avoid 'labelling' individuals with a disability and the tendency to treat people as 'patients'.

It is clear that people with learning disability are not in as good health as the general population. This was demonstrated by status data from the Welsh Health Survey which found that, *'people with learning disability scored lower on all attributes, apart from bodily pain (where they scored higher) and vitality (where they scored the same), as the general population'* (Welsh Office, 1995). The 'attributes' included physical functioning, social functioning, general health, physical, emotional and mental health.

Within this population, there exist commonly occurring co-morbid conditions, including neurological and genetic disorders, which have life long consequences e.g. epilepsy, Down's syndrome, tuberous sclerosis and cerebral palsy. People with a learning disability are at increased risk of developing illness for three reasons (Figure 3).

Figure 3: Reasons for increased risk of health problems

-
- 1) The specific association between health problems and causes of learning disability.
 - 2) The non-specific association between health problems and learning disability.
 - 3) The risks that arise from living and environmental conditions.

(HoN, 1995)

The Health of the Nation Strategy for people with Learning Disabilities (DoH, 1995) identifies some health problems or disabilities, which are common in people with a learning disability (Figure 4).

Given the evidence that people with learning disabilities are not in good health and will most likely have difficulty in communicating or identifying their needs, they will require assistance to access generic health services. Whether carers recognise this need for support will depend partly on their understanding of their duty of care and of the features of the client population, which make it difficult for them to recognise this need for themselves.

Figure 4: Common health problems and estimated prevalence rates

■ Communication problems	■ Hearing problems	■ Eyesight problems
■ Obesity	■ Behavioural problems	■ Epilepsy
■ Psychiatric illness	■ Respiratory disorders	■ Mobility problems.
Estimated prevalence		
■ Communication difficulties	50 -80%	(Mansell, 1993)
■ Visual and auditory defects	60%	(Vitiello & Behar, 1992)
■ Sub-optimal nutrition	30%	(Bond et al., 1997)
■ Behavioural and		
Emotional disorders	up to 50%	(Bouras & Drummond, 1992)
■ Epilepsy	20-50%	(Corbett et al., 1975)
■ Cerebral Palsy/other		
Motor impairments	20-30%	(McLaren & Bryson, 1987)

Espie and Brown (1998) make a valid point that social care staff are often poorly trained to enable people to benefit from health care services. They may see the symptoms but not recognise the significance, not know the risk of certain disorders that are associated with learning disability or not think that it is serious enough to get medical help (Kinell, 1987). A person may not then be supported in accessing medical attention. This is reflected in the fact that people with learning disabilities

have higher rates of illness but use health services less than the general population (HoN, 1995).

A study by Howells (1986) found a high level of poor health following a survey of a group of adults with a learning disability attending a training centre. This ranged from easily treatable conditions such as skin disorders and head infestations to more chronic conditions such as diabetes, epilepsy and bronchitis. It was suggested that these health related problems were compounding the communication difficulties of these people (Howells, 1986). Langham et al. (1994) found that carers had difficulty in dealing with mental health or emotional problems and had problems in both accessing medical help and conveying the problems to the doctor. Both these studies concur with Espie and Brown's (1998) concerns that carers have poor skills in enabling their clients to benefit from adequate health care.

In Scotland, the Scottish Health Advisory Service (SHAS) recommendations have prioritised health care and have recommended that health boards co-ordinate a response to address some of the difficulty people with learning disabilities have in accessing the appropriate services. As part of this, it is recognised that carers require training (Figure 5).

Figure 5: Training needs of care workers

-
- 1) To recognise distress and symptoms associated with the particular disorders which their clients are known to have.
 - 2) To recognises symptoms and disorders in people with learning disabilities.
 - 3) To know how and where to report these and how to refer to the GP.

(Espie & Brown, 1998)

Health service providers for this client group have a duty to address the way in which they disseminate information but they also have a role to play in increasing carer's awareness of the particular health care needs of people who they work with.

Part and parcel of increasing carer's awareness of the healthcare needs of this client group is the need to ensure that they have a basic understanding of the facts and features associated with learning disability.

Clearly fundamental to this is a knowledge of the key diagnostic criteria of a learning disability as stated by the American Association on Mental Retardation (AAMR, 1992). These criteria are widely accepted as used by professionals working in this field however there is an ongoing debate regarding the interpretation of the criteria and the wording used in the definition.

1.5 Defining Learning Disability

Burton (1997) focused on the issue of developing a definition of intellectual disability and highlighted the key problems in formulating a definition that describes a particular client group. Firstly there is the issue of finding an acceptable term to use, that conveys the correct message regarding the characteristics of the client group. 'Imbecile', 'idiot', 'feeble-minded' (used in 1944 Education Act) and 'subnormal' (1959 Mental Health Act, England and Wales), were all used as terms to describe this population. Historically, changes in terminology have been based on the rationale that using more 'positive' terms will result in improved attitudes and subsequently improved interactions with others (Hastings et al., 1993). They often reflect a change in a philosophy within different professions and reflect a greater sensitivity to the people it describes. However, evidence suggests that all these labels are associated with negative connotations and that changing the labels is not a long term solution to altering societies treatment of people with a learning disability (Hastings et al., 1993).

There are advantages and disadvantages of each of the terms adopted highlighted by Burton (1997). The term 'learning disability' has been used in UK since the late 1980's but implies that there is a problem in the ability to learn, which may not necessarily be the key issue. Alternatively, 'intellectual disability' is used in Australasia and more obviously suggests that the main difficulty is with intellectual functioning rather than social functioning. The difficulties in social functioning are assumed to be a result of intellectual impairment rather than another cause. The term

'mental retardation' is used in North America but is perceived to be offensive to the client group and has generally been rejected. In addition, Burton (1997) commented that it is inaccurate as retardation or slowness may not be the pertinent problem.

The need to develop a clear definition of a learning disability has become essential following the changes within the National Health Service and the implementation of the Community Care Act (1990). The introduction of the concept of purchasers resulted in an increase in the number of health and social care agencies and organisations involved in service provision for this client group. All services need to be working with the same basic understanding so that the correct support can be accessed. Mansell (1996) comments that in the past, individual services may have worked from their own criteria in deciding whether someone would be best served by the specialist learning disability services or a different service.

Burton (1997) makes a debatable point that a learning disability is not defined by any clear cut off point and that there is a difficulty in deciding where to draw the line between those eligible for a service and those not. It has been argued that using the term learning disability to describe a person's needs is stigmatising and unhelpful but without a defining term, those people who require specialist support would not receive it through the general service (Burton, 1997). The question is how to develop an acceptable definition that can adequately distinguish between people with learning disabilities and the general population.

Historically, up until the end of the nineteenth century, a learning disability was defined in terms of deficits in what is now termed ‘adaptive behaviour’. It wasn’t until the 20th century that a learning disability was conceptualised in terms of a deficit in intellectual functioning (Wright & Digby, 1996).

The American Association on Mental Retardation (AAMR) devised the most widely accepted definition and classification system. The most recent revision can be seen in Figure 6 (Luckasson et al., 1992).

Figure 6: AAMR 1992 Definition of ‘Mental Retardation’

Mental retardation (learning disability) refers to substantial limitations in present functioning.

It is characterised by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following adaptive skill areas:

- | | | | |
|------------------------------|------------------|------------------------------|---------------|
| ■ social/interpersonal skill | ■ communication | ■ self-care | ■ home living |
| ■ use of community resources | ■ self-direction | ■ functional academic skills | |
| ■ work | ■ leisure | ■ health and safety. | |

Mental retardation manifests before age 18.

‘Substantial limitations in present functioning’ is taken to mean that there is a reduced ability to learn new skills, understand new information and perform certain everyday skills. These difficulties must be related to limitations in social, practical and conceptual intelligence. Other areas of functioning may not be affected e.g. temperament, health.

‘Significantly sub-average intelligence functioning’ is defined as an IQ of 70 to 75 or below (approximately 2 standard deviations below the mean). General intellectual functioning is defined by the intelligence quotient (IQ) obtained by assessment with valid, reliable and standardised individually administered IQ tests, e.g. Wechsler Adult Intelligence Scale – 3rd Edition (1998).

In addition to impaired intellectual functioning, there must also be significant limitations in adaptive skills or activities of daily living for an individual to be classified as having a learning disability. Adaptive skills are measured in relation to what would be appropriate for a person’s age and have been described as *‘the skills that will help an individual fit in to a social niche, and the ability to change one’s behaviour to suit the demands of the situation’* (Evans, 1991). Such limitations must not result from a person’s culture or language or from motor or sensory limitations.

Intellectual impairment alone is not sufficient to diagnose a learning disability for two reasons. Firstly, intelligence assessments contain an element of error and secondly, it must be demonstrated that there are generalised impairments in functioning by specifying at least two limitations in adaptive skills.

The age of onset before 18 years of age represents the age at which an individual usually assumes the roles and responsibilities of an adult in Western societies e.g. voting for Members of Parliament. This is not universal and in other countries with different cultures and values, an alternative age criterion might be more appropriate.

There are problems though as the terms are socially constructed in that what it means, how it is measured and who counts as having a learning disability has changed over time (Wright & Digby, 1996; Trent, 1995). The definition varies between countries, depending on political, ideological, economic and cultural factors (Fryers, 1993).

1.6 Specific issues relating to people with a learning disability

The Health of the Nation Strategy for people with a learning disability (DoH, 1995) highlighted some specific areas of difficulty for this client group, which will briefly be reviewed along with other pertinent areas.

1.6.1 Communication difficulties

Compared with the normal pattern of development, people with a learning disability experience distortion and delay in their acquisition of language (Rondal, 1996).

Early communicative ability is associated with later social development (Bailey et al., 1996) and communication difficulties are associated with the development of difficult to manage behaviours. Individuals may have difficulties in expressing

themselves verbally and/or understanding spoken words but may be able to communicate in other ways. Manual signs or symbol based communication boards are often used to accompany speech as they are often easier to teach and signs and symbols can be clearly associated with actions and objects. To be effective, a communication system must be understood and reinforced by others (Remington, 1998).

1.6.2 Hearing loss

The prevalence of hearing loss in people with a learning disability is not clear and estimates range from 5-60% with average occurrence estimated at 25 % (Kerr et al., 1996). Hearing loss is more prevalent in older age groups (Cooke, 1988). Hearing loss often goes undetected (Ellis, 1986) and can lead to behavioural disturbance that can be mistaken as psychotic episodes. In a sample of 500 people, 39.4% were found to have hearing loss (Yeates, 1992). Objective tests are available for the identification of hearing loss and treatment can improve speech intelligibility.

1.6.3 Visual disorders

The prevalence of visual disorders in people with a learning disability ranges from 28-80%, depending on the type of population surveyed (McCulloch et al., 1996) but an average occurrence is estimated at 40% (Kerr et al., 1996). A highly significant trend towards poorer vision with increasing level of intellectual disability has been found and common diagnoses associated with this group include; squint, cataracts,

disorders of the optic nerve and refractive errors (Woodruff et al., 1980; McCulloch et al., 1996).

1.6.4 Nutrition and Obesity

Estimates of the prevalence of obesity are somewhat contradictory. Some authors state that obesity is up to twice as prevalent in people with a learning disability as in the general population, with estimates of up to one in four people with a learning disability being obese (Turner & Moss, 1996; Welsh Office, 1995). Others have found that there were no significant differences between a sample of people with a learning disability and those without (Murphy et al., 1992). There does seem to be heterogeneity within this population, with underweight and overweight individuals represented (Simila & Niskanen, 1991). Allison et al. (1998) conclude that obesity is common in people with a learning disability but not necessarily more so than in the general population. Many syndromes associated with learning disability also have obesity as a pathonomic feature e.g. Prader-Willi and Down's syndrome (Allison et al., 1998).

People with a learning disability may have difficulty understanding dietary education and if they are not supported in their choice of food and lifestyle are at risk of becoming overweight or malnourished. As with the general population, obesity is a risk factor for cancer, respiratory and cardiovascular diseases and diabetes (Allison & Pi-Sunyer, 1995; Pi-Sunyer, 1993). The majority of people with a learning disability do not do moderate or vigorous exercise (Turner, 1996; Welsh Office,

1996) which leads to a further increased risk of disease. Prescribed drugs (antiepileptic and neuroleptics) often have side effects, which may include weight gain (Bernstein, 1987).

1.6.5 Epilepsy

Epilepsy is a common co-morbid condition associated with learning disability. The prevalence of epilepsy increases with the severity of learning disability with an estimated prevalence of 50% in those with profound learning disability, 6% in those with mild learning disability and a total prevalence of 20% (Richardson et al., 1979; Corbet, 1981; Shepherd & Hoskins, 1989; Coulter, 1993). The significance of these figures becomes apparent when compared to the total general population prevalence of 0.5-1% and a lifetime prevalence of 2-5% (Goodridge & Shorvon, 1983; Brown et al., 1993; Muir et al., 1996). There are clear implications for the quality of life and care needs of people with learning disability and epilepsy.

1.6.6 Psychiatric Illness

People with a learning disability are at risk of developing mental health disorders due to the complex interaction of biological, social, psychological and family factors (Bouras et al., 1999). Biological factors include the higher level of brain damage, sensory impairments and syndromes such as Down's syndrome that are associated with a person with a learning disability. By definition, people with a learning

disability have cognitive impairments, which often result in poor coping mechanisms (O'Hara & Sperlinger, 1997).

Personality development is influenced by a number of factors that can also apply to those without a learning disability. People with a learning disability often grow up in a restricted and disadvantaged environment characterised by a lack of opportunities for exercising choice, a lack of non-disabled peers, as well as low expectations and over-protection of others (Bouras et al., 1999). There are often difficulties associated with the bonding of disabled children with their parents, accompanied by parental acceptance of the disability and the influence this has on the later development of self-control/esteem in the individual (O'Hara & Sperlinger, 1997). People with a learning disability are observed to have increased experiences of failure, rejection, separation and bereavement, without the necessary resources to cope with these events (Bouras et al., 1999). Not surprisingly they may have difficulty in forming and maintaining relationships, which may lead to an increase in emotional and behavioural problems.

People with a learning disability have reduced resources in terms of cognitive ability to cope with the demands placed on them by the things they experience. This has an impact on the development of personality and the development of adaptive processes and as a result, people with a learning disability are more vulnerable to developing emotional difficulties. The prevalence of co-morbid mental illness is about 3-4 times greater than the general population (HMSO, 1996) and prevalence rates are estimated at 10-14% (Kerr et al., 1996). Despite this, a diagnosis may be missed because of the

difficulties people with a learning disability often have in firstly recognising their feelings and then describing and expressing themselves. An observation by carers or family of behavioural or biological changes is often used in diagnosis (Holland & Murphy, 1990). Adults with a learning disability suffer from the same types of mental disorder as people with normal intellectual functioning.

Depression and anxiety are the most common disorders. Depression is strongly associated with low levels of social support and poor social skills (Reiss, 1994) and studies suggest (Nezu et al., 1995) that people with a learning disability become depressed for similar reasons as people without a learning disability. Studies show that 10-30% of people with a learning disability have generalised anxiety states (Ollendick et al., 1993) and panic attacks, specific phobias, post-traumatic stress disorder and obsessive-compulsive disorders are also common.

1.6.7 Behavioural difficulties

'Severe challenging behaviour refers to behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of community services.'

(Emerson et al., 1987)

The term challenging behaviour has been used to describe high levels and combinations of self-injurious, aggressive, destructive, sexually inappropriate or socially unacceptable behaviour e.g. faecal smearing. It is estimated that between 15-20% of people with a learning disability presents significant and active challenges

to those that live and work with them (Keirnan & Qureshi, 1993). Challenging behaviours are more likely to present in:

- ☐ Boys and men
- ☐ People aged between 15 and 35 years
- ☐ People with severe learning difficulties
- ☐ People with specific syndromes e.g. autism
- ☐ People with sensory difficulties, specific difficulties with communication or mobility

(Emerson, 1998)

A number of different causes may contribute to the expression of challenging behaviour in an individual. Bouras et al. (1999) summarise the sources of possible causes into six categories:

- ☐ biological causes
- ☐ a response to a poor environment (low social interactions, a barren environment with few activities)
- ☐ a communicative act (expressing pain, anger, sadness or confusion)
- ☐ a response to mental trauma
- ☐ an association with mental illness
- ☐ a learned behaviour

Environmental consequences and contingencies can shape behaviour through positive and negative reinforcement, often mediated by other people such as staff working with them (Emerson, 1998).

1.6.8 The Law

General law, which applies to everyone in the population also, applies to people with a learning disability. However, specific legislation covers sexual abuse, exploitation, treatment of mental illness and conviction and disposal following criminal offences (McKay, 1997). For example, Section 106 of the Mental Health (Scotland) Act 1984 is designed to protect women with a learning disability from exploitation by making it an offence for a man to knowingly have unlawful sexual intercourse with a woman with a learning disability i.e. outside of marriage.

A further example pertains to offenders who have a learning disability. The Scottish Home and Health Department's circular, 'Interviewing of Mentally Handicapped or Mentally Ill Persons', recommends that police should always try to interview people with a learning disability in the presence of an 'appropriate adult'. An appropriate adult can be a relative, carer or someone with experience of people with a learning disability who is not a police officer. The role of the appropriate adult is to facilitate communication.

Despite the distinctions made in some areas of law, people with a learning disability have the same rights as the general population as stated by the general Assembly of the United Nations (1971).

'The mentally retarded person has the same rights as other human beings, including the right to proper medical care, an inherent right to respect for their human dignity and the same civil rights as other human beings. Disabled persons shall be able to avail themselves to qualified legal aid when such aid proves indispensable for the protection of their persons.'

(General Assembly of the United Nations, Declaration on the Rights of Mentally Retarded Persons, 1971).

Having rights is clearly of no use if an individual has difficulty in expressing or exercising their rights or if others do not recognise those rights. This is a further example of the need for people working with this client group to recognise the limitations of the people with which they work and to understand their role in enabling people with a learning disability to access their rights.

In summary, a number of studies have identified that there is a lack of awareness of the fundamental characteristics of a learning disability in residential care staff, which clearly has an impact on both staff and client functioning. The evidence suggests that there is a need to remind all staff about the basic defining characteristics of learning disability and what it means in everyday functioning (McKenzie et al., 1999a).



‘...Supporting people with a learning disability is not an intuitive skill, it will be the adoption of effective working methods backed by good management and staff training which will result in the delivery of appropriate support, not a further appeal to ordinariness’

(Felce, 1999, pp. 8).

1.7 The Present Study

The literature has identified that social care staff as a group are not clear about the defining features of a learning disability. It has been argued that this lack of basic understanding can be detrimental to the quality of life of people in their care as well as their own health and well being. Social care staff have a legal obligation to be aware of the issues relevant to the people they work with including those highlighted by the document Health of the Nation Strategy for people with Learning Disabilities (DoH, 1995).

At present there is no formal, objective way of assessing staff knowledge of the important features, facts and issues relating to people with a learning disability. The literature has shown that without a basic understanding of the features of this client group, it is difficult to implement care packages or to develop further skills in working with people with a learning disability.

1.7.1 Aims

It is the aim of this study to,

1. Develop, pilot and establish the reliability and validity of a questionnaire that covers pertinent issues relating to people with a learning disability (Learning Disability Knowledge Questionnaire – LDKQ). It is intended that it will be used to identify general levels of knowledge of learning disability and training needs in social care staff working with this client group.
2. To develop, pilot and evaluate an information manual to be used in conjunction with the questionnaire as a training tool with social care staff.

1.7.2 Hypotheses

1. The LDKQ will be a reliable and valid tool for assessing levels of knowledge in social care staff.
2. Social care staff with experience of working with people with a learning disability will have significantly higher levels of knowledge than a control group without experience.
3. People with greater experience of working with people with a learning disability will have significantly higher levels of knowledge.
4. Post training scores on LDKQ will be higher than pre-training scores.
5. Levels of knowledge as assessed by LDKQ will be retained over time.

METHOD

2.1 Design

The study involved the development of a questionnaire consisting of 30 items relating to pertinent facts and issues about learning disability. The questionnaire was piloted on a sample of social care staff working in residential and day centres for people with a learning disability (n=92). The questionnaire was analysed for reliability and validity. The second part of the study involved the development of an information manual, which followed the format of the questionnaire and contained further material selected from the literature relating to each of the 30 items. A sample of social care staff (n=32) took part in a training session and levels of knowledge were assessed at three stages, before training (n=32), immediately after training (n=32) and at one-month after training (n=24). The effectiveness and durability of the training session was evaluated. Comments were collected from the participants regarding aspects of the questionnaire and training session.

2.2 Participants

A group of social care staff (n=92) working in residential and day services for adults with a learning disability was recruited to complete the LDKQ. Of those participants approached to take part in the study, no-one refused, however there were people who were absent from work on the day of the administration of the LDKQ. The participants all worked directly with people with a learning disability but did not

have formal training and did not work within the NHS. The residential services fell within the remit of the independent sector and consisted of small-staffed group homes for adults with a learning disability. The day services fell within the remit of the local authority and their role was to provide routine, structured and meaningful activities for adults with a learning disability on a daily basis. From this group, a sample of 23 social care staff completed the LDKQ on a second occasion one month later, to assess test-retest reliability. A sample of 32 social care staff all working in residential settings with adults with a learning disability completed the training session. Eight subjects in the training group failed to complete the LDKQ at one month follow up and it was not possible to investigate the reason for this.

A sample of the general population (n=35) with no experience of working with people with a learning disability was recruited to complete the LDKQ in order to provide a comparison group in terms of levels of knowledge. This sample was not matched to the social care sample in terms of age or socio-economic status but was a 'convenient' sample of people who were approached and agreed to take part in the study. There was a range of occupations within this group including unskilled / untrained people to those who had education to degree level.

Table 1 contains the demographic information and characteristics relating to each group.

Table 1: Total number in sample, sex, mean age and mean years working in learning disability for each group.

Groups	Sex		Age				Experience			
	Male	Female	Missing data	Total (n)	Mean (yrs)	SD	Range (ys)	Mean (yrs)	SD	Range (yrs)
Total social care staff	28	38	26	92	38.09 n=35	10.83	19-57	8.16 n=67	6.00	0-24
Test-retest group	9	9	5	23	38.17 n=12	10.65	25-57	6.23 n=22	5.50	1-20
Training group	9	23	0	32	39.38 n=32	11.39	21-61	5.70 n=31	5.99	0-23
General population	12	23	0	35	39.54 n=26	15.39	16-68	N/A	N/A	N/A

2.3 Procedure

2.3.1 *Development of item pool*

Thirty-nine items were initially developed based on information taken from the literature on a variety of areas relating to learning disability (Appendix 1). For example,

Aetiology e.g.

A virus cannot cause a learning disability.

A head injury cannot cause a learning disability.

Diagnosis e.g.

People with a learning disability have significantly low intelligence.

A learning disability can be diagnosed with a brain scan.

Health e.g.

Eyesight problems are more common in people with a learning disability.

Epilepsy is more common in people with a learning disability.

Rights and the law e.g.

People with a learning disability can get married.

People with a learning disability have the same rights as the general population.

A forced choice 'True or False' format was chosen as the questions were based on factual knowledge regarding learning disability rather than opinion. A 'True or False' format is relatively straightforward and quick to complete. It is familiar to individuals of most social and educational background therefore is likely to achieve a high return rate (Moser & Calton, 1979). In addition, a standard administration procedure and scoring procedure was required for the standardisation of the questionnaire. Although not viewed as being essential, the same number of 'True' and 'False' responses and approximately the same number of positively and negatively worded questions to answers were chosen.

2.3.2 Validity

'Content validity represents a judgement regarding the degree to which a test provides an adequate sample of a particular domain'

(Guion, 1977)

Content validity of the item pool was achieved by consulting professionals in the learning disability field for comment. An initial pilot of the LDKQ was completed by a range of professionals (n = 21) including 3 clinical psychologists, 3 speech and language therapists, 3 psychiatrists, 2 occupational therapists, 2 trainee clinical psychologists, 1 music therapist and 7 community nurses. It was also given to a small sample of social care staff (n=6), and a staff group working in an assessment and treatment unit for people with a learning disability (n=4). Comments were received regarding the relevance of items to the area of learning disability, whether

any areas had been omitted or over-represented, the format and ‘readability’ of items, and ways in which the LDKQ could be improved.

After the initial pilot, ambiguous questions and those questions that respondents thought to be ‘too easy’ were omitted and other questions were reworded. After considering the comments, the questionnaire was reduced to 30 items (Appendix 2).

2.3.3 Readability Statistics

Readability scores provide information about the reading level of the document. Each readability score bases its rating on the average number of syllables per word and words per sentence. An evaluation of ‘ease to read’ was made, using the Flesch formula (Flesch, 1948).

2.3.4 Flesch Reading Ease Score

This formula rates text on a 100-point scale; the higher the score, the easier it is to understand the document. For most standard documents, a score of approximately 60 to 70 is acceptable. The Flesch-Kincaid Grade Level score rates text on a United States grade-school level. A score of ‘8.0’ means that an eighth grader can understand the document. For most standard documents, a score of approximately 7.0 to 8.0 is acceptable.

Table 2: Readability statistics for the LDKQ

Formula	Total LDKQ	Learning disability omitted
Flesch reading ease	45.1	77.9
Flesch-Kincaid grade level	8.3	3.3

Table 2 contains the results of both the Flesch readability analyses. Initially the LDKQ appeared to be more difficult to read than an average document. However, the Flesch formula is partly calculated on average number of syllables per word and the inclusion of words ‘learning disability’ increased this average score. It was assumed that the population being investigated (social care staff) would easily recognise and understand the words ‘learning disability’ and would find them easy to read. When the words ‘learning disability’ were omitted, the LDKQ became very much easier to read and suitable for a reading age of approximately 7 years.

2.4 Administration of the LDKQ

The questionnaire was given to a sample of social care staff working with people with a learning disability (n=92), based on the recommendation of 2-3 times the number of sample as test items (Goldstein & Houston, 1984). The LDKQ took approximately 10 minutes to complete individually without consultation with other

members of the group. Participants were read a set of instructions in a standardised manner,

'The LDKQ contains facts about a learning disability so all the answers are either true or false. Please complete the information at the top of the sheet, which is for my use only and will be kept confidential. Please try and answer all the questions without missing any out and let me know when you have finished'.

2.5 Training Session

A brief 'training' or 'information session' was offered to a sample of staff (n=32) consisting of five separate groups of residential care staff. Table 1 contains the relevant demographic information.

The training session lasted approximately one hour and took place before the regular staff meeting onsite at each organisation. It was decided to locate the session in a familiar setting based on research evidence that suggests some staff become inhibited and reticent about becoming involved when training in larger groups and in places that are unfamiliar (Binney, 1992). The session was structured and guided in format as recommended by Stammers and Patrick (1975).

A literature search was completed on each of the areas included in the LDKQ and relevant research information was collated into a manual, following the format of the LDKQ (Appendix 3). The question was stated, followed by the 'True or False'

answer and a brief explanation of the reason for the answer. A cross-reference was given pertaining to the relevant appendix attached to the manual, which provided more detailed supplementary information about key areas in the questionnaire for further reading. Participants were able to keep a copy of the manual as a reference source to encourage retention and assimilation of knowledge and information.

The LDKQ was administered and followed immediately by the information session. The relevant answers and a brief explanation of the research findings relating to each question were presented in order to reinforce the key points. To make the session as interactive as possible and to maintain attention, participants were asked to suggest the correct answer and then they marked their own questionnaire. This encouraged discussion and debate about each item.

The first LDKQ's were collected and a second copy was distributed and completed in the same way in order to assess levels of knowledge after training. Participants again marked their own answers and discussion and questions were encouraged.

The LDKQ was redistributed to all available participants (n=24) one month later to assess the durability of training.

2.6 Evaluation of Training

An evaluation of the LDKQ and training session was completed by participants in the training sample (n=32), in the form of questionnaire (Appendix 4). It was based

on recommendations proposed by Van Gelder, Gold & Schalock (1996) to assess 'learner reactions' to training. A 5 point likert scale was used with ratings from 'good' to 'poor' to assess four questions about the LDKQ: clarity of the questionnaire, relevance of the material to the job, length and format. Five questions were asked in relation to the training: clarity, length and usefulness to the job, value of the information and structure of the session. Two-open ended questions were asked relating to what the participant found most and least useful about the session. General comments were also requested.

2.7 Analysis

The SPSS version 10 for Windows statistical package was used to analyse the data.

2.7.1 *Item Efficiency*

Hypothesis 1 was initially investigated by assessing the sensitivity of items to differing levels of knowledge by calculating ease of response to each item. Ease of response was obtained from the proportion of the sample that answered an item correctly. For items that can be scored incorrect or correct, item ease is calculated by the number of subjects who pass an item divided by the number of subjects who responded to the item (Kline, 1993). If a given ability were assumed to be randomly distributed, the expected 'difficulty' would be 0.5, although there is the possibility that this could also reflect guessing on dichotomous items. However, if it is 0.0 or 1.0 then the item is too difficult or too easy, respectively and is effectively useless, as

it offers no discrimination among subjects. Items scoring values of between 0.2 and 0.8 are thought to be discriminating (Kline, 1993).

2.7.2 Reliability

The goal of reliability is to estimate errors in measurement and suggest ways of minimising the errors (Kline, 1993). Errors can arise from conditions of the experiment or observer, over a number of repeated measurements errors will be random and will tend to cancel each other out. The mean of all the measurements is more accurate than a single measurement. Across a large number of individuals the causes of errors are assumed to be so varied that measurements errors act like random variables (Kline, 1993). There are a number of methods of testing reliability and test-retest and internal consistency reliability were chosen as the most appropriate for this study.

2.7.3 Test-Retest Reliability

Test-retest reliability refers to the administration of the same test to the same group of people on two different occasions. The reliability is estimated by the correlation between the two sets of scores. Although a three month period between the two testing times is recommended (Kline, 1993), due to time constraints of the study, the LDKQ was re-administered to a sample of respondents (n=23) after a period of one month. The total scores of respondents on occasion 1 was correlated with the total scores on occasion 2. The variability of within subject scores on individual items on

both occasions and between subjects on each occasion was analysed as follows. Responses were placed into one of four possible categories, which reflected the reliability of response, by each subject.

- Category 1: Incorrect occasion 1, incorrect occasion 2 (reliable response, suggesting a belief in an incorrect answer).
- Category 2: Correct occasion 1, correct occasion 2 (reliable response, suggesting a belief in a correct answer).
- Category 3: Correct occasion 1, incorrect occasion 2 (unreliable response, suggesting ignorance of correct answer).
- Category 4: Incorrect occasion 1, correct occasion 2 (unreliable response, suggesting ignorance of correct answer).

Question difficulty was analysed in relation to subject responses to investigate whether easier questions answered more reliably, for example subjects obtaining correct responses on occasion 1 were compared with those obtaining correct responses on occasion 1 and 2. The question of whether items with a higher level of unreliability (those answered incorrectly on occasion 1 and 2), were those which subjects found more difficult was investigated.

2.7.4 Internal Consistency Reliability

Internal consistency reliability estimates the reliability of a test based upon the items in the test and the average intercorrelation among items. The procedure involved

administering the LDKQ to a group of individuals in the target population and computing the correlation among items. The average correlation was computed and the KR20 (Kuder-Richardson, 1937) equation was used to estimate reliability. It is intended for tests with items that have only two possible alternatives (True or False). The calculation is equivalent to Cronbach's alpha (Cronbach, 1951) which is the most commonly used test of internal reliability and was chosen for use in this study.

2.7.5 Sensitivity

The sensitivity of the LDKQ to discriminate between differences in levels of knowledge was analysed by plotting the normal distribution of the total scores for the social care staff sample. The distribution of ease of response to each item was plotted to investigate whether there was a normal distribution of item difficulty. Total scores on the LDKQ were also plotted for the general population sample.

An independent samples t-test was used to investigate whether experience of working with people with a learning disability has an effect on knowledge of a learning disability as measured by the LDKQ (Hypothesis 2).

Pearson's product moment coefficient correlation was used to investigate whether there was a significant association between years of experience of working with people with a learning disability and knowledge as assessed using the LDKQ in the social care staff sample (Hypothesis 3).

2.8 Efficiency of Training

To investigate hypothesis 4, that scores on the LDKQ would be higher after training, total scores on occasion 1 and occasion 2 were compared using a within subject, repeated measures design. A repeated measures analysis of variance (ANOVA) was used to assess the effect of training over time on subject scores on the LDKQ.

To investigate whether levels of knowledge are retained over time (Hypothesis 5), total scores on occasion 2 and occasion 3 were compared using repeated measures ANOVA. A point-biserial correlation (Pearson product moment coefficient) was calculated to investigate the association between scores pre-training, immediately after training and at one month after training.

It was thought to be of interest to investigate whether or not individual questions were answered in a similar way after training. An analysis of the reliability of responses over time was carried out in the same way as in the test-retest reliability analysis.

2.9 Validity

'A test is always valid for some purpose and so is more valid in some circumstances than in others'

(Vernon, 1960)

If a test measures what it claims to measure then it is said to be valid, but, unlike reliability, there is no single validity coefficient for a test (Kline, 1993). There are a number of ways the validity of a test can be assessed and content validity has been described earlier. Face validity is another form of validity and was assessed by participants completing an evaluation form.

2.9.1 Evaluation

The scores from the separate questions were collated and descriptive statistics used to summarise participant's views. Qualitative comments were collated and incorporated into the general discussion about the LDKQ and training session.

RESULTS

3.1 Hypothesis 1:

The LDKQ will be a reliable and valid tool for assessing levels of knowledge in social care staff.

Internal consistency of the LDKQ was assessed using a standardised measure of reliability, Cronbach's alpha (1951). Table 3 shows descriptive statistics and inter-item correlations for the whole scale based on a sample of 92 social care staff.

Table 3: Descriptive statistics for the LDKQ and inter-item correlations (n=92)

Statistics for Scale	Mean	Variance		Std Dev	N of Variables	
	17.0435	13.0750		3.6159	30	
Inter-item Correlations	Mean	Minimum	Maximum	Range	Max/Min	Variance
	.0377	-.3823	.6387	1.0210	-1.6706	.0149

The mean inter-item correlation suggests that there is little association between items in terms of consistency of responses by subjects on individual items.

Item reliability was measured by correlating each item with the total score. An alpha score was produced with each item systematically deleted (Alpha if item deleted), as shown in Table 2. The 'alpha if item deleted' values do not differ significantly

indicating that no single item has a dramatic effect on the internal consistency of the questionnaire.

The overall alpha score for the LDKQ 0.54 (Table 4) suggests that the questionnaire has a low to moderate internal consistency.

Table 4: LDKQ reliability

Alpha coefficient for LDKQ (n=92)	
Total alpha coefficient (standardised alpha)	0.54 (0.54)
Range of scores for each item	0.50 (Q1) – 0.56 (Q5, Q26)

This suggests that the items are not measuring the same core variable and the questionnaire as a whole may be measuring a number of different variables. This may be predicted given the type of items in the questionnaire. Each item measures an individual fact about a learning disability and it could be argued that items would not be expected to be internally consistent in the same way as they should be in a test of attitude, where homogeneity of items would be desirable. The questionnaire aims to provide a measure of knowledge of a learning disability, this calculation suggests that a response on one item is not reliably related to responses on other items. Coefficient alpha shows the expected correlation of a test of a given number of items with an alternative form with the same number of items.

The small negative individual item-total correlation's (Table 5) demonstrate why the alpha coefficient is low. The reliability of a measure is related to the homogeneity of items or their intercorrelations. Cronbach's alpha correlates items with total score. An item with a high reliability will produce a value close to 1 indicating that if a subject has scored highly on the questionnaire then they are likely to have scored correctly on that item.

On the LDKQ, questions 5, 8, 9, 11 and 26 have small negative correlations, which are close to zero. This suggests that these items correlate poorly with total scores and can be regarded as unreliable items. Even if a subject scored highly overall, these values suggest that they were answering in an unreliable and perhaps random way to these items. The item with the highest corrected item-total correlation is question 1. This correlates best with the total scores suggesting that when people score highly overall they are more likely to answer this question correctly. However, the value of .39 can be considered relatively low and indicates that even though it has the highest correlation, it still cannot be considered a reliable item.

The range of item-total correlations (minimum -.03 – maximum .39) suggests that there was not a strong relationship between scores on individual items and total scores. The item-total correlations suggest that subjects' overall score on the LDKQ may not be associated with responses to individual items.

Table 5: Item-total Statistics for LDKQ (n=92)

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item- Total Correlation	Alpha if Item Deleted
Q1	16.80	11.74	.39	.50
Q2	16.62	11.97	.25	.52
Q3	16.37	12.19	.20	.53
Q4	16.45	12.71	.03	.55
Q5	16.30	13.09	-.07	.56
Q6	16.37	12.65	.06	.54
Q7	16.83	12.39	.18	.53
Q8	16.45	12.95	-.03	.56
Q9	16.35	12.98	-.03	.56
Q10	16.22	12.55	-.14	.53
Q11	16.82	13.03	-.04	.56
Q12	16.77	12.29	.19	.53
Q13	16.28	11.96	.31	.51
Q14	16.38	11.84	.31	.51
Q15	16.60	12.33	.14	.53
Q16	16.78	12.26	.20	.53
Q17	16.45	11.88	.28	.51
Q18	16.68	12.50	.10	.54
Q19	16.22	12.85	.03	.55
Q20	16.49	11.79	.30	.51
Q21	16.48	11.75	.32	.51
Q22	16.12	12.90	.06	.54
Q23	16.42	12.75	.02	.55
Q24	16.57	12.09	.21	.52
Q25	16.22	12.13	.30	.52
Q26	16.40	13.01	-.05	.56
Q27	16.30	12.52	.11	.54
Q28	16.30	12.74	.04	.55
Q29	16.75	12.12	.23	.52
Q30	16.48	12.34	.14	.53

This may suggest that at least some subjects answered in a random way and that a correct response on one item was not associated with a correct response on a different item. This suggests that knowledge is not consistent across the areas covered in the LDKQ.

The items with small negative correlations do not seem to be those items which the sample generally found 'difficult' to answer as indicated by the low proportion of subjects scoring the item correct (Table 6). The item-total correlations allow for a more detailed analysis of subjects' responses to individual items in relation to the overall scores. The ease of response data provides information about which items the sample as whole found 'difficult' but it does not allow for investigation of the association between correct item scores and overall score. Question 11 appears to be the only item that the sample group found 'difficult' to answer, shown by the low proportion of the sample scoring it correctly (0.23) and also had a small negative item-total correlation (-0.04).

3.1.1 Sensitivity to Differing Levels of Knowledge

The sensitivity to differing levels of knowledge and ease of response or item difficulty in the LDKQ was measured by calculating the proportion (percentage) of subjects who scored correctly on each question (Table 6). Total correct responses ranged from a minimum of .22 (22%) to a maximum of .92 (92%). All values fall generally within the accepted cut-off range of between .20 (20%), 'difficult' to .80 (80%), 'easy'.

Table 6: The proportion (%) of correct response to each item (n=92)

Question	Proportion of sample scoring correctly (%)
Question 1	.24 (24%)
Question 2	.42 (42%)
Question 3	.67 (67%)
Question 4	.60 (60%)
Question 5	.74 (74%)
Question 6	.67 (67%)
Question 7	.22 (22%) *
Question 8	.60 (60%)
Question 9	.70 (70%)
Question 10	.83 (83%)
Question 11	.23 (23%)
Question 12	.27 (27%)
Question 13	.76 (76%)
Question 14	.66 (66%)
Question 15	.45 (45%)
Question 16	.26 (26%)
Question 17	.60 (60%)
Question 18	.36 (36%)
Question 19	.83 (83%)
Question 20	.55 (55%)
Question 21	.57 (57%)
Question 22	.92 (92%) **
Question 23	.62 (62%)
Question 24	.48 (48%)
Question 25	.83 (83%)
Question 26	.64 (64%)
Question 27	.74 (74%)
Question 28	.74 (74%)
Question 29	.29 (29%)
Question 30	.57 (57%)

The question answered correctly by the highest proportion of subjects and the only one to fall out-with the acceptable range was question 22 (.92, 92%) '*people with a learning disability can get married*'. The question that was answered correctly by the lowest proportion of subjects was question 7 (.22, 22%) '*sexual problems are more common in people with a learning disability*'. Question 22 may be regarded as the question subjects found 'easier' (*) and question 7 may be regarded as the question they found the 'difficult' (**).

There was a range of item difficulty over the whole questionnaire (Table 6) with four items proving relatively 'easy' for the total sample of subjects to answer correctly. Question 22 (.92, 90%) as above. Question 10, '*a learning disability is not a type of mental illness*', question 19, '*a head injury cannot cause a learning disability*' and question 25, '*communication problems are more common in people with a learning disability*', all fell just outwith the recommended range of item difficulty. The proportion of subjects scoring correctly was .83 (83%).

Item analysis of the individual questions revealed that although there was a range in terms of ease of response, this was not normally distributed (Figure 7). The distribution could almost be described as bimodal with a cluster of six questions answered correctly by a lower proportion of subjects and described as 'difficult' (Q1, Q7, Q11, Q12, Q16 and Q29). Two items fall on the mean value of .57 (57%), (Q21 and Q30). Eight items lie close to the average value of .57 (57%) with values in the range .60 (60%) – .67 (67%) (Q3, Q4, Q6, Q8, Q14, Q17, Q23 and Q26) with all other items lying either side of this point.

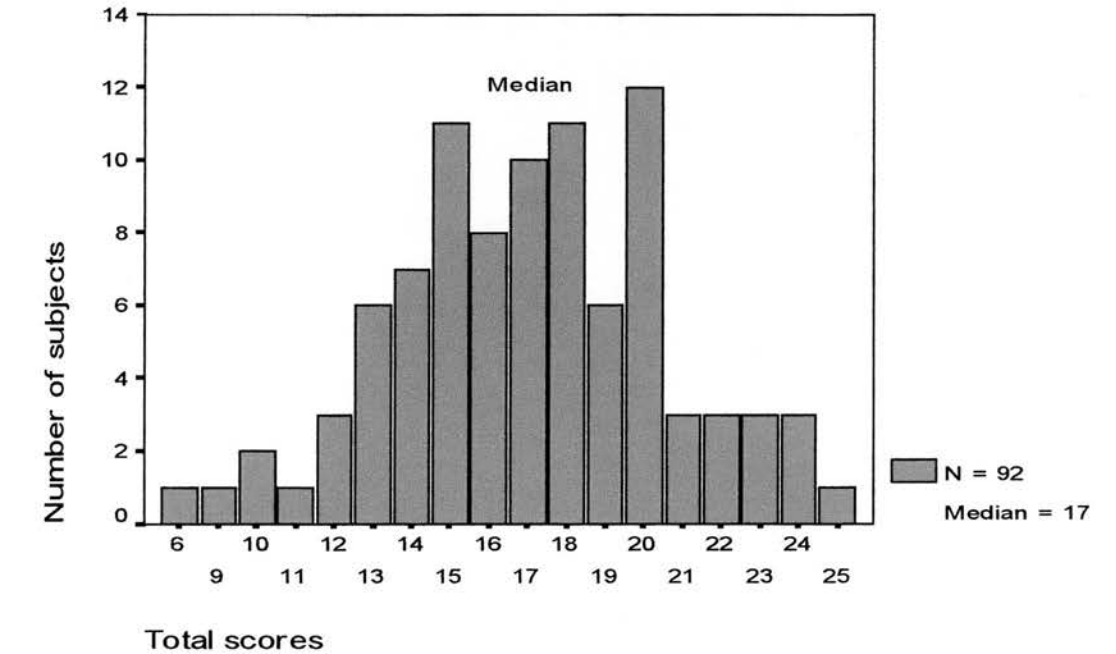
Figure 7: Item mean correct score Stem-and-Leaf Plot

Frequency	Stem &	Leaf
6.00	2 .	234679
1.00	3 .	6
3.00	4 .	258
3.00	5 .	577
8.00	6 .	00024677
5.00	7 .	04446
3.00	8 .	333
1.00	9 .	2

Stem width: .10
Each leaf: 1 case(s)

Total scores across subjects appear to be relatively normally distributed (Figure 8) as the values for kurtosis (0.196, standard error 0.498) and skewness (-0.191, standard error 0.251) could be regarded as small.

Figure 8: Social care staff sample total scores



There are no significant differences between scores for male and female subjects in this sample.

Table 7: Comparison of total scores between male and female subjects

Group Statistics

SEX		N	Mean	Std. Deviation	Std. Error Mean
TOTAL SCORES PER SUBJECT	MALE	28	16.79	3.54	.67
	FEMALE	38	17.39	3.61	.59

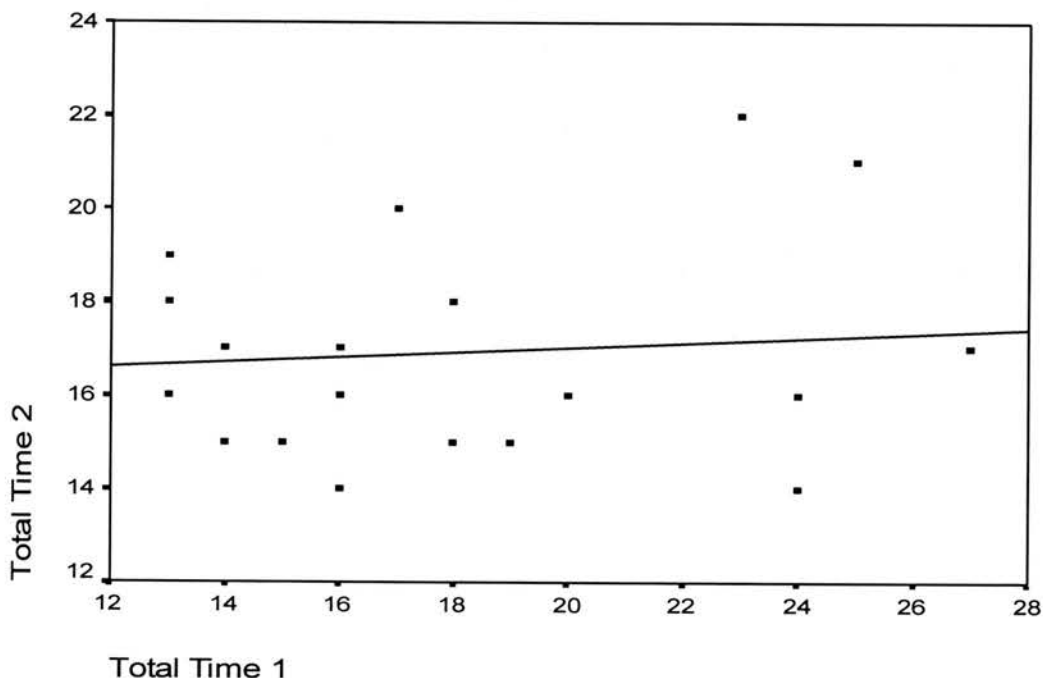
Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
TOTAL SCORES PER SUBJECT	Equal variances assumed	.000	1.000	-.855	62	.396	-.77	.90	-2.57	1.03
	Equal variances not assumed			-.857	58.603	.395	-.77	.90	-2.57	1.03

3.1.2 Test-Retest Reliability

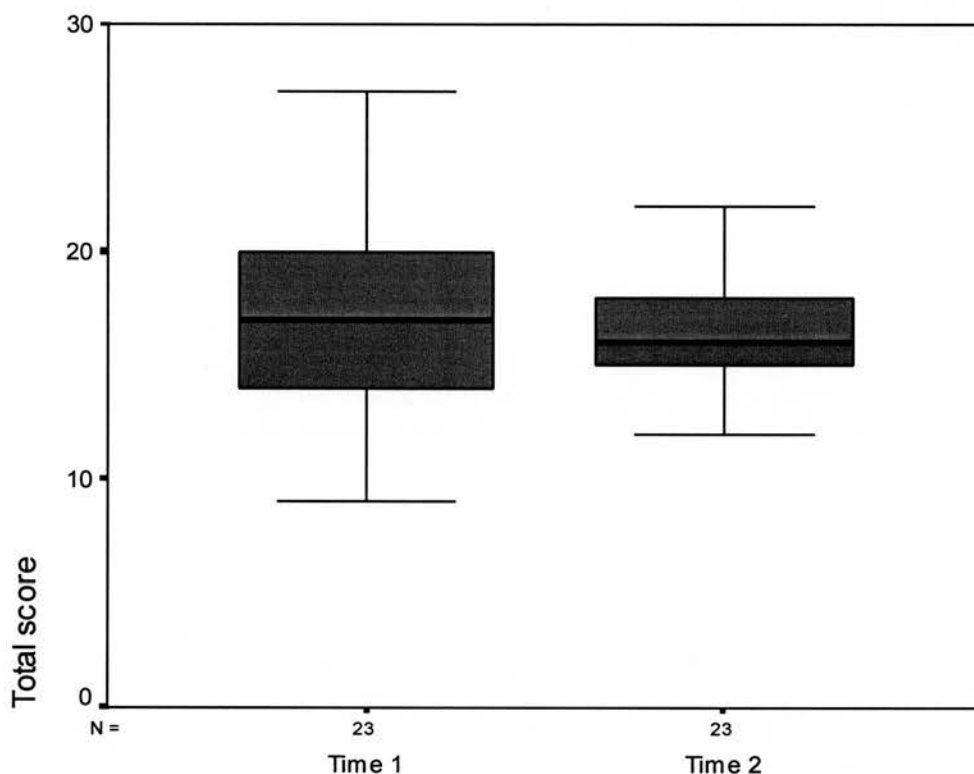
Test-retest reliability was calculated by correlating total scores on Time 1 with total scores on Time 2 for a sample of the total population ($n = 22$) using Pearson product moment correlation coefficient. One score was omitted in the calculation as it was considered to be an outlier. The results indicate that scores on the LDKQ varied over time, $r = 0.102$, ($p < 0.652$) (Figure 9) and scores on test-retest were not stable. The degree of spread of scores was wide indicating that there was very little relationship between scores over time. The correlation coefficient indicates that approximately 1% of the variability in total scores can be related to levels of knowledge over time whereas the other 99% are related to other factors. This result may suggest that subjects were 'guessing' on many of the items, leading to the lower correlation coefficient.

Figure 9: The relationship between total scores on Time 1 and total scores on Time 2 in a sample of social care staff ($n=22$)



The median score on Time 1 was 17 (Range 9-27) but on Time 2 this had decreased to 16 (Range 12-22) (Figure 10). This supports the finding that scores varied over time both in terms of median values and range of scores with a greater spread of scores being found on Time 1.

Figure 10: Median scores and range of scores of subjects in the test-retest sample



Given that participants total scores on the LDKQ were not reliable over time, it was thought to be of interest to examine subject responses to each question in more detail. To this end, an analysis of subject responses was carried out to investigate which questions were answered reliably on Time 1 and Time 2. This provided further information relating to ease of response of items by indicating whether items

answered incorrectly were due to either misconceptions or lack of knowledge in the subjects.

For each separate item there are four categories of response, shown in Table 8. An incorrect response on Time 1 and Time 2 (category 1) suggests subjects hold misconceptions about the question or a belief in an incorrect answer whereas a correct response on Time 1 and Time 2 (category 2) suggests a belief in a correct answer. Questions answered correctly on only one occasion are classed as unreliable (categories 3 and 4) and perhaps suggest that subjects are randomly guessing and do not possess the necessary knowledge.

The association between ease of response of the questions (Table 6) and the reliability of subject responses (Table 8) is shown in Table 9. It appears that responses suggesting a reliable response and a belief in a correct answer (category 2) are associated with items that a higher proportion of the total sample scored correct and could be classed as 'easier' (Range .66 - .92). Responses suggesting misconceptions (category 1) are associated with items that the lowest proportion of the total sample scored correct and could be classed as 'difficult' (Range .22 - .36). Unreliable responses (categories 3 and 4) are those responses suggesting a poverty of knowledge and are associated with items that an average proportion of subjects in the total sample scored correct classed as 'average' in terms of ease of response (Range .48 - .57).

Table 8: Reliability responses to individual items on Time 1 and Time 2

Question	CATEGORY 1	CATEGORY 2	CATEGORY 3	CATEGORY 4
	Incorrect Time 1&2 (%)	Correct Time 1&2. (%)	Correct Time 1 Incorrect Time 2 (%)	Incorrect Time 1 Correct Time 2 (%)
1	73.9	8.7	4.3	13.0
2	43.5	30.5	17.4	8.7
3	26.0	26.0	30.4	17.4
4	17.4	34.8	21.7	26.0
5	4.3	52.2	8.7	34.8
6	0	95.7	4.3	0
7	73.9	8.7	0	17.4
8	34.8	43.5	13.0	8.7
9	21.7	43.5	21.7	13.0
10	13.0	43.5	30.5	13.0
11	43.5	4.3	30.5	21.7
12	73.9	21.7	0	4.4
13	0	82.6	4.3	13.0
14	39.1	34.8	17.4	8.7
15	39.1	26.1	21.7	13.0
16	73.9	13.0	8.7	4.4
17	47.8	30.5	8.7	13.0
18	52.2	17.4	17.4	13.0
19	0	73.9	13.0	13.0
20	30.4	17.4	21.7	30.4
21	34.8	43.5	13.0	8.7
22	4.3	78.3	4.3	13.0
23	26.0	52.2	13.0	8.7
24	26.0	30.5	21.7	21.7
25	8.7	82.6	8.7	0
26	8.7	60.8	17.4	13.0
27	8.7	73.9	8.7	8.7
28	13.0	60.9	13.0	13.0
29	60.8	13.0	4.3	21.7
30	21.7	39.1	8.6	30.4

Table 9: The association of ease of question and reliability of responses over time to individual questions

Category of difficulty & reliability category	Questions
'Easy' & correct 'reliable'	5, 6, 8, 9, 10,13, 14, 19, 21, 22, 23, 25, 26, 27, 28, 30
'Average' & 'unreliable'	4, 15, 20, 24, 30
'Difficult' & incorrect 'reliable'	1, 2, 7, 11, 12, 16, 18, 29

Exceptions to the above categorisation include question 3 ‘*a learning disability is acquired during childhood*’. This item was generally answered unreliably or incorrect over time by a large proportion of subjects (91%) but the proportion of the *total* sample scoring it correct at one point in time was relatively high (.67, 67%). Question 17 ‘*mental retardation and learning disability are not the same thing*’, was answered incorrectly (answered reliably) over time by 48% of subjects but the proportion of the total sample scoring it correct at one point in time was within the ‘average’ range.

The results suggest that those questions found ‘easy’ or ‘difficult’ by the total sample were generally answered more reliably by this test-retest sample, suggesting perhaps that subjects possess the relevant knowledge, hold misconceptions or simply lack knowledge in the area in question. Those questions falling within the ‘average’

range for ease of response were generally answered unreliably possibly indicating a poverty of knowledge about particular areas.

Questions that subjects appeared to hold misconceptions about included those referring to the diagnostic criteria of a learning disability (question 1, 2) and issues relating to diagnosis (questions 11, 17, 18) and the specific health needs of this client group (questions 7, 12, 16, 29). Questions reflecting a poverty of knowledge or apparent uncertainty included those relating to diagnosis (questions 3, 9, 10, 11, 15), causes of a learning disability (question 4) and health needs (questions 20, 24, 30). Questions that over 80% of subjects answered correctly over time included those referring to residential services (question 6), whether a learning disability can be cured (question 13) and communication difficulties in this client group (question 25).

3.2 Hypothesis 2:

Social care staff with experience of working with people with a learning disability will have significantly higher levels of knowledge than a control group without experience.

An independent samples t-test was calculated between the total social care sample (n=92) and a sample taken from the general population with no experience of working with people with a learning disability (n=35) (Table 10). A significant difference was found between the two sample groups $t_{(125)} = 3.43$, ($p < 0.001$) suggesting that staff working with people with a learning disability do indeed possess a greater knowledge about facts and issues relating to the client group with which they work.

The median total score of 15 of the general population sample indicates performances of no better than chance and suggests that people without experience of working with this client group have very little specific knowledge. The distribution of scores for the general population is not significantly skewed nor is there a problem with kurtosis (Figure 11). The range of scores, 12-20 indicates that there is not a great variation in levels of knowledge issues relating to learning disability in a sample of subjects without relevant experience.

Table 10: Independent T-test examining the difference in scores between groups with different levels of experience working in learning disability

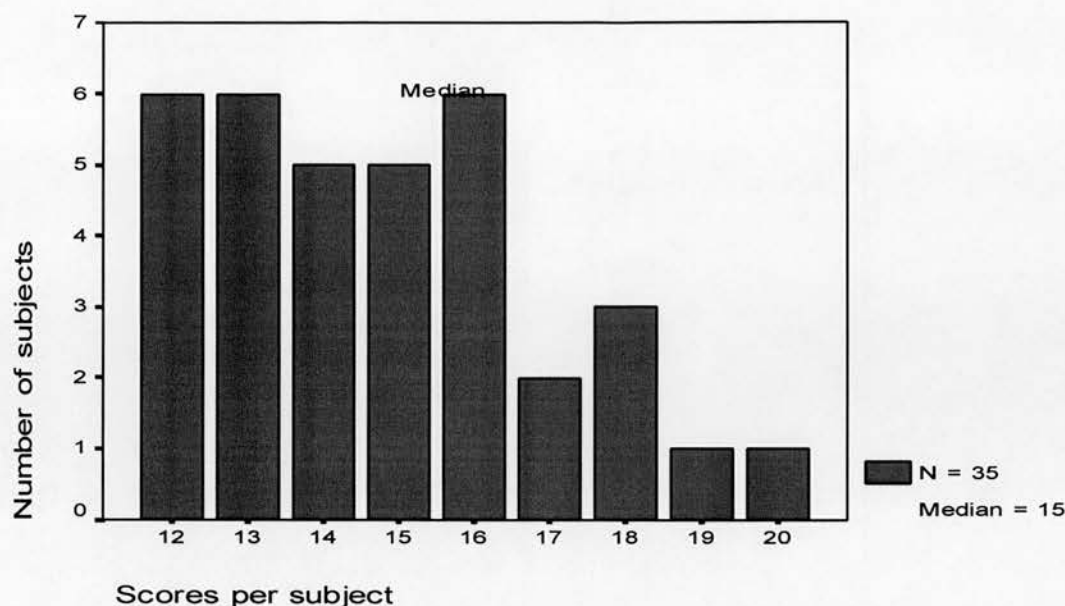
Group Statistics

YEARS OF EXPERIENCE IN WORKING IN		N	Mean	Std. Deviation	Std. Error Mean
SCORES PER SUBJECT	no experience	35	14.80	2.19	.37
	experience	92	17.04	3.62	.38

Independent Samples Test

	Levene's Test for Equality of Variances		t-test for Equality of Means							
									95% Confidence Interval of the Difference	
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper	
SCORES PER SUBJEC										
	Equal variances assumed	7.058	.009	-3.433	125	.001	-2.24	.65	-3.54	-.95
Equal variances not assumed			-4.243	100.502	.000	-2.24	.53	-3.29	-1.19	

Figure 11: General population sample total scores



On closer examination of individual items, it appears that there are some items in which a higher proportion of the general population sample scored correctly (Table 11). Questions relating to diagnosis, aetiology, the law and service provision were among those a greater proportion of the general population sample scored correctly. The difference between the groups ranged from 3% on question 14 '*hyperactivity is a type of learning disability*' to 33% on question 26 '*people with a learning disability have the same rights as the general population.*' On two items the proportion of subjects scoring correctly was the same in both groups, question 4 '*a learning disability cannot be inherited*' (60% correct) and question 10 '*a leaning disability is not a type of mental illness*' (83% correct). A higher proportion of the social care group scored the remainder of the items correctly when compared to the general population group. The difference between the groups ranged from 5% on question 5 '*a virus cannot cause a learning disability*' to 51% on question 17 '*mental*

retardation and learning disability are not the same thing'. This suggests that there are some items where knowledge between the groups varies very little but on others items there is a greater discrepancy perhaps suggesting that social care staff group are more knowledgeable.

Table 11: Items answered correctly by a higher proportion of a general population sample than a social care staff sample

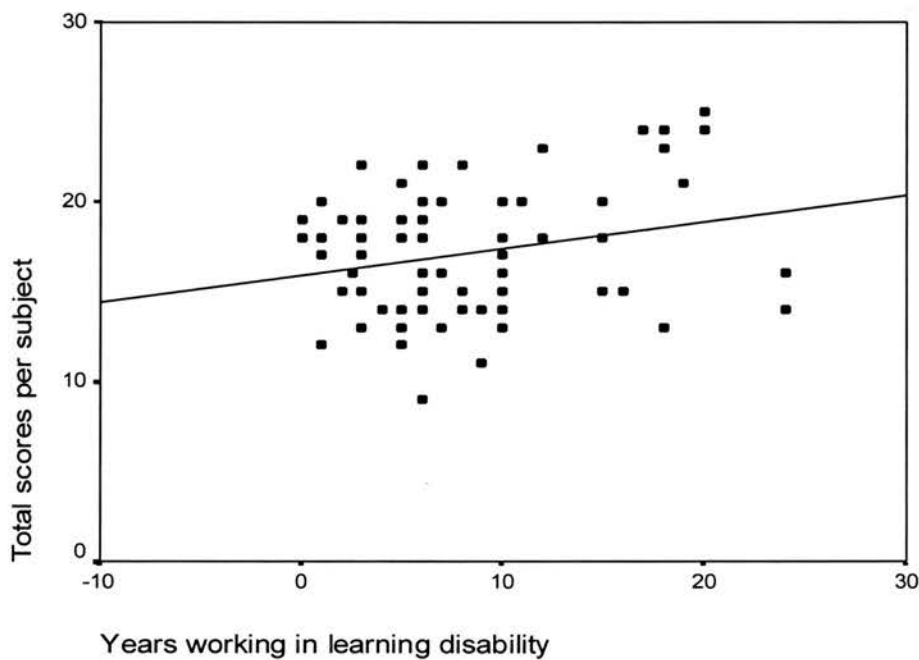
Question category	Social care staff (% correct)	General population (% correct)
Diagnosis		
Question 9	70	83
Question 11	23	51
Question 14	66	69
Question 28	74	94
Aetiology		
Question 27	74	100
Law		
Question 22	92	97
Question 23	62	89
Question 26	64	97
Service provision		
Question 6	67	94

3.3 Hypothesis 3:

People with greater experience of working with people with a learning disability will have significantly higher levels of knowledge.

Using Pearson Product Moment Correlation coefficient, a significant but weak association was found between years of experience of working with people with a learning disability and total score on the LDKQ, $r_{(65)} = 0.242$, ($p < 0.05$). The degree of scatter of scores is wide (Figure 12) suggesting that there is a positive but weak relationship between years of experience of working with people with a learning disability and total score on the LDKQ. The correlation coefficient indicates that approximately 6% of the variability in total scores is related to years of experience of working in this area and 94% is related to other factors.

Figure 12: The relationship between total scores and years of experience working in learning disability.

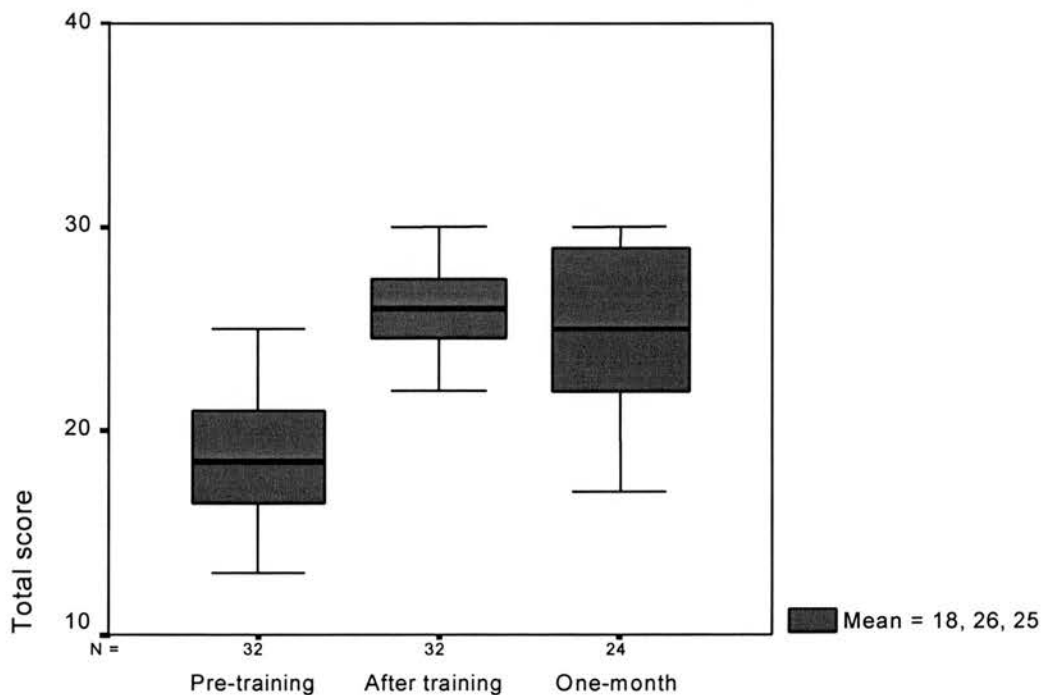


3.4 Hypothesis 4:

Post-training scores on LDKQ will be higher than pre-training scores.

From the results (Figure 13) it is clear that scores both immediately after and one month after are higher than total scores pre-training. The range of scores decreased pre-training to immediately after training from 12 to 9 points. The minimum total score increased by 8 points and the highest score obtained by subjects increased by 5 points to a maximum score on the LDKQ of 30. The median total values achieved by subjects decreased slightly immediately after training to one month after training. The range of scores increased from 9 points to 13 points indicating that there is a decrease in total scores by some subjects over time.

Figure 13: Median values and ranges of total score pre, immediately after and one month after training.



A significant effect over time was found when scores for pre, immediately after and one month after training were compared (Table 12).

Table 12: Analysis of total scores over time

Effect		Value	F	Hypothesis df	Error df	Sig.
TIME	Pillai's Trace	.852	63.3666	2.000	22.000	.000

A repeated measures ANOVA of subjects' total scores pre-training, immediately after training and at one-month after training was performed to investigate where this effect over time occurred. The results suggest (Table 13) that that there is a significant difference between total scores pre-training (level 1) and immediately after training (level 2) $F_{(1,23)}=131.25$ ($p<0.001$). This indicates that subjects retained a significant proportion of the information provided in the training session when assessed immediately after the session.

Table 13: A comparison of total scores pre-training, immediately after training and at one-month after training, in a sample of social care staff

Tests of Within-Subjects Contrasts

Measure: MEASURE_1

Source	TIME	Type III Sum of Squares	df	Mean Square	F	Sig.
TIME	Level 1 vs. Level	1335.042	1	1335.042	131.245	.000
	Level 2 vs. Level	28.167	1	28.167	1.988	.172
Error(TIME	Level 1 vs. Level	233.958	23	10.172		
	Level 2 vs. Level	325.833	23	14.167		

An analysis of subject responses to individual questions immediately before and after training (Table 14) suggests that although correct responses increase after training, there are still some subjects who respond incorrectly on both occasions.

Table 14: Analysis of responses to questions immediately before and after training.

Question	Correct Time 1 N=32 (%)	Correct Time 2 N=32 (%)	Incorrect Time 1 Incorrect Time 2 N=32 (%)	Correct Time1 & Time 2 N=32 (%)
1	22	100	0	22
2	56	100	0	56
3	59	84	6	50
4	69	94	6	69
5	81	88	6	75
6	66	78	6	50
7	19	97	3	19
8	53	56	29	28
9	75	81	9	66
10	88	78	3	69
11	44	88	9	38
12	34	94	6	31
13	75	97	3	75
14	81	100	0	81
15	50	88	3	41
16	28	88	12	28
17	63	84	6	53
18	38	94	6	25
19	72	81	3	56
20	75	47	12	31
21	5	94	6	59
22	97	100	0	97
23	84	97	0	84
24	59	59	12	31
25	91	100	0	91
26	81	97	3	81
27	81	84	0	66
28	66	94	0	59
29	44	97	3	44
30	50	72	6	28

This pattern of responding suggests a belief in an incorrect answer and poverty of knowledge, despite being provided with information to the contrary during the training session. A small proportion of subjects (3% per question) responded in this manner to questions 7, 10, 13, 15, 19, 26 and 29 (Appendix 2). Questions 3, 4, 5, 6, 12, 17, 18, 21 and 30 (Appendix 2) indicate that 6% of subjects per question were incorrect on both occasions. A further 9% of subjects responded in this way to question 11 and 12 % each to questions 16, 20 and 24. Twenty nine percent of subjects responded incorrectly on both occasions to question 8, *'the law for people with a learning disability is the same as for everyone'*.

Despite this, scores on each question on the LDKQ increased in all but 3 cases.

Correct responses on question 10 fell by 10% and on question 20 they fell by 28%.

Correct scores on question 24 remained unchanged between the two assessments.

3.5 Hypothesis 5:

Levels of knowledge as assessed by LDKQ will be retained over time.

The repeated measures ANOVA (Table 14) calculated to investigate where the significant difference in scores over time occurred showed that there was no significant difference between total scores immediately after training (level 2, time 2) and one-month after training (level 3, time 3), $F_{(1,23)}=1.988$ ($p<0.172$). This supports the hypothesis that levels of knowledge as assessed by LDKQ will be retained over time. The average scores at each point in time show that there was a slight decrease in mean scores between level 2 (immediately after training) and level 3 (one month after training) which would explain the trend towards significance reflected in the F value (Table 15).

Table 15: Mean total scores pre-training, immediately after training and at one-month after training.

TIME				
Measure: MEASURE_1				
TIME	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1	18.708	.738	17.181	20.236
2	26.167	.402	25.334	26.999
3	25.083	.773	23.484	26.682

To investigate whether there was an association between total scores pre, immediately after and at one-month after training, a Pearson Product Moment

Correlation coefficient was calculated (Table 16). A significant relationship was found between the scores pre-training and immediately after training but the correlation coefficient is relatively low indicating that the scores do vary over time $r_{(32)} = 0.475$ ($p < 0.01$). Approximately 23% of the variability in total scores could be related to the impact of training and 72% related to other factors.

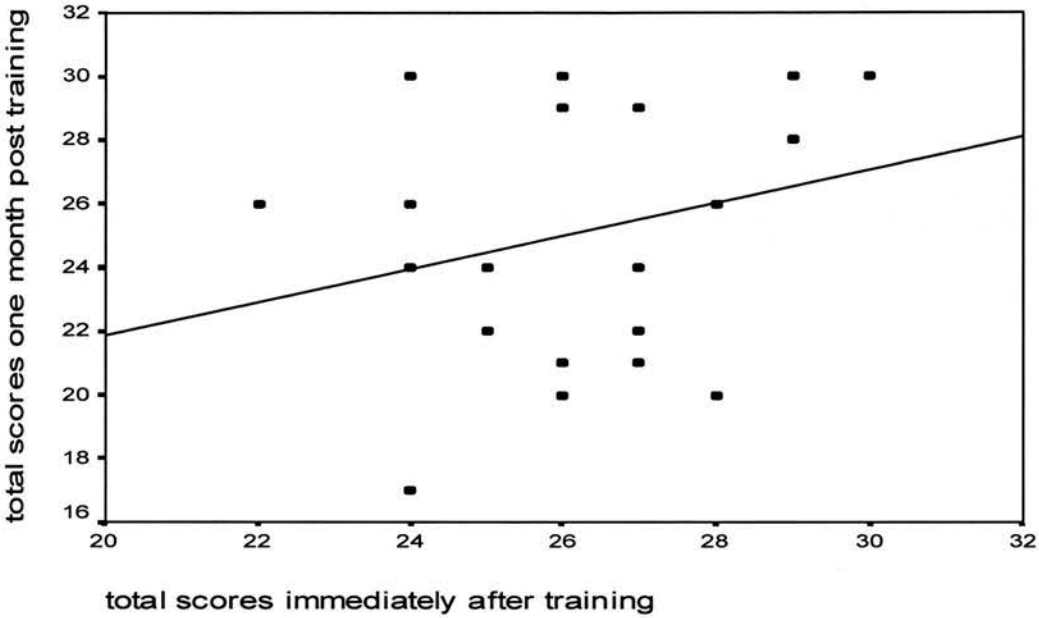
A significant relationship was not found between scores pre-training and at one-month after training $r_{(32)} = -0.076$ ($p = 0.681$) as would have been expected. Subjects total scores assessed one-month after receiving training did not relate to those pre-training. There was not an association between scores immediately after and at one-month after training $r_{(32)} = -0.056$ ($p = 0.761$) (Figure 14). The degree of scatter of scores was wide and suggests that subject total scores were not stable over time and subjects who scored highly immediately after training may score lower at one month and vice versa. There were 8 missing subjects at one-month post training, which may have had an effect on the outcome of the correlation.

Table 16: Relationship between total scores pre training, immediately after training and at one-month follow-up

		Total scores Pre-training	Total scores after training
Total scores after training	Pearson Correlation	.475**	
	Sig. (2-tailed)	.006	
	N	32	
Total scores one month post training	Pearson Correlation	-.076	-.056
	Sig. (2-tailed)	.681	.761
	N	32	32

** . Correlation is significant at the 0.01 level (2-tailed).

Figure 14: The relationship of subject total scores immediately after and at one month after training



The results show that *total* scores of subjects increase immediately after training and scores remain high at one-month after training but it was thought to be of interest to investigate whether individual questions were answered in the same way on both occasions. To obtain this information, an analysis of subject responses to individual items was calculated (Table 17).

Table 17: Analysis of responses to individual items immediately after training (T2, n=32) and one month after training, (T3, n=24)

Question	Correct T2 (%)	Correct T3 (%)	Correct T2 & T3 (%)	Incorrect T2 correct T3 (%)	Correct T2 incorrect T3 (%)	Incorrect T2 incorrect T3 (%)	Total unreliable responses (%)
1	100	92	92	0	8	0	8
2	100	100	100	0	0	0	0
3	84	83	67	17	17	8	42
4	94	79	79	0	13	8	21
5	88	67	58	8	21	8	37
6	78	58	42	17	17	8	42
7	97	92	92	0	8	0	8
8	56	67	42	25	13	17	55
9	81	92	71	21	8	0	29
10	78	75	63	13	13	13	39
11	88	58	46	13	38	4	55
12	94	96	92	4	4	0	8
13	97	92	88	0	8	0	8
14	100	88	88	0	13	0	13
15	88	71	67	0	29	0	29
16	88	96	88	4	0	4	8
17	84	79	75	4	8	8	20
18	94	96	88	4	4	0	8
19	81	75	67	8	17	4	29
20	47	79	42	38	0	21	59
21	94	100	88	8	0	0	8
22	100	100	100	0	0	0	0
23	97	83	100	0	17	0	17
24	59	83	54	21	0	17	38
25	100	100	100	0	0	0	0
26	97	83	83	0	13	4	7
27	84	71	58	13	25	0	38
28	94	71	71	0	25	4	29
29	97	96	88	4	4	0	8
30	72	88	79	8	0	13	26

Seven questions were scored correctly by a higher proportion of subjects one-month after training (Time 3) than immediately after training (Time 2), questions 8, 9, 16, 20, 21, 24 and 30 (Appendix 2). On twelve questions, the proportion of correct responses fell when assessed one-month after training, questions 4, 5, 6, 11, 14, 15, 17, 19, 23, 26, 27 and 28. Finally, the proportion of correct answers remained remarkably similar on both occasions on eleven items, questions 1, 2, 3, 7, 10, 12, 13, 18, 22, 25, and 29.

An analysis of subject responses to questions immediately after and at one-month after training reveals that some questions are answered more reliably over time than others. The following questions (Table 18) were answered in a way that suggests either guess work, a return to previously held belief or a change in response due to an increase in knowledge over time. Unreliable responses are those answered as incorrect Time 2/correct Time 3 or correct Time 2/ incorrect Time 3. Only those that were answered unreliably by a defined proportion of the sample (over 25%) are included (n=24).

Table 18: Individual questions answered unreliably when assessed immediately after
and at one month after training

Question		% sample
1.	A learning disability cannot be acquired during childhood.	34
5.	A virus cannot cause a learning disability.	29
6.	Most people with a learning disability live in residential care.	34
8.	The law for people with a learning disability is the same as for everyone.	38
9.	A learning disability and a learning difficulty are not the same thing.	29
10.	A learning disability is a type of mental illness.	26
11.	Autism is not a type of learning disability.	51
15.	Dyslexia is a type of learning disability.	29
19.	A head injury can cause a learning disability.	25
20.	Behaviour problems are not more common in people with a learning disability.	38
27.	There are more women than men with a learning disability.	38
28.	A learning disability can be diagnosed with a brain scan.	25

3.6 Evaluation

Participants (n=28) completed an evaluation form (Appendix 4) at the end of the training session consisting of 9 questions rated on a likert 5 point scale (Table 19) and were asked for qualitative comments.

Table 19: Summary of subject rating of the LDKQ and training session

Question	Median (mode) score 1= poor 5= good	Range
1. Clarity of the LDKQ	4 (4)	2-5
2. Length of the LDKQ	4 (4)	2-5
3. Format of the LDKQ	4 (4)	2-5
4. Relevance of the questions to my job	5 (5)	3-5
5. Clarity of the training session	4 (3)	3-5
6. Length of the session	3 (3)	2-5
7. Usefulness of the material to my job	4 (4)	3-5
8. Value of the information to my job	4 (4)	2-5
9. Structure of the session	4 (4)	2-5

The median ratings of 3 to 5 on all aspects of the LDKQ and the training session suggests that subjects found the exercise worthwhile, useful and relevant to their job.

The modal values indicate that the most common evaluation for each aspect of the

LDKQ and training session was between 3 and 5. Further qualitative information was obtained by requesting comments about subject's views of the session and questionnaire.

Participants were asked, *'What did you find most useful?'* and the responses have been summarised below.

- ┐ *"The information was useful in focusing attention on learning disabilities. The day to day work often surpasses the need to keep abreast with current legislation etc".*
- ┐ *"Some of the factual information".*
- ┐ *"Information in the questionnaire"*
- ┐ *"Learning different things about learning disability that I didn't know".*
- ┐ *"Finding out the answers to some questions I had not considered and then was surprised to find out".*
- ┐ *"I was not aware of some of the facts about learning disability. It also made me realise that I did not read some of the questions properly".*
- ┐ *"Clarifying the difference between learning disability and learning difficulty".*
- ┐ *"Whole session relevant, informal and relaxed".*
- ┐ *"I found the information given very useful and I feel that I learned a lot from it".*
- ┐ *"The most useful thing I found was what the abilities of the people were".*
- ┐ *"I thought the information was very interesting and it made me think about the tenants that I work with".*

- ┘ *“As a student I found it useful a it gave an idea about the signs and symptoms of a learning disability and how it affects people”*
- ┘ *“The information booklet is a good and well worth a read. The whole session was an eye opener”.*
- ┘ *“The answers! Really informative and we need reminding of the nature of learning disability”.*

The comments made by subjects indicate they did indeed learn new things about a learning disability or had their knowledge refreshed. The replies also suggest that it prompted them to think about specific people with which they work. Having the information booklet to keep appeared to be helpful, providing a reference to look back on.

Participants were also asked, *‘What did you find least useful?’* The comments have been summarised below.

- ┘ *“The structure of the feedback session. I would have preferred it in a different format as there was too much technical information at the end of a working day”.*
- ┘ *“The wording of the questionnaire could be better. Some of the questions are misleading if you do not read them properly”.*
- ┘ *“More information could have been given before hand. The questions were difficult to read”.*
- ┘ *“Some information I already knew”.*
- ┘ *“The questions could be more straightforward”.*

- ┃ *"I would have preferred 'agree' or 'disagree' instead of 'true' or 'false'".*
- ┃ *"All the 'nots' in the questions".*

Most participants who provided comments made reference to the wording of the questions, which they found generally confusing and difficult to read. One individual felt that they knew most of the information and questioned the content of the information. The timing of the session, at the end of the day for some participants was not thought to be conducive to acquiring new knowledge.

General comments were also requested and are summarised below.

- ┃ *"I have 11 ½ years experience working with people with a learning disability but was surprised at what I had forgotten or was not up to date on. I found the questionnaire interesting, although some of the questions were worded 'back to front' encouraging the reader to think more carefully before answering."*
- ┃ *"It was good to get a copy of the information manual. I feel I can keep going back to it for reference or to keep my knowledge fresh in my mind".*
- ┃ *"I found the questionnaire interesting as I didn't realise how many everyday functions of a person with a learning disability could be put down as a learning disability or could restrict someone in their activities".*
- ┃ *"Being relatively new to this work, I found it quite informative".*
- ┃ *"It may been useful for the session to be more interactive with more discussion".*
- ┃ *"Although designed to make people think, the way some questions were worded appeared confusing. Some answers were surprising but did relate to the context*

from which they had been taken. My work experience made me think or draw different conclusions”.

- ▢ *“It was not too lengthy which was good. The requests were clear and easy to understand. The questions were easier to understand the second time around”.*
- ▢ *“It would be beneficial to if there were small scenarios and each staff member were to fill in how they would deal with each situation. This would give you a better outlook on how workers relate to different aspects of having a learning disability”.*

Issues that were mentioned by participants included how the session had prompted them to reconsider their view of the people they work with and sometimes draw different conclusions than they had done in the past. In terms of the wording of the questions, one participant thought it helped people concentrate and carefully consider their answer, which is an alternative interpretation, than most participants gave.

Suggestions for adaptations to the sessions were put forward and generally implied that more discussion and interaction would be useful.

DISCUSSION

4.1 Hypotheses

The present study aimed to investigate a number of hypotheses, firstly that the LDKQ would be a reliable and valid tool for assessing levels of knowledge of a learning disability in social care staff. Secondly, that social care staff with experience of working with people with a learning disability would have significantly higher levels of knowledge than a control group without experience. Thirdly, people with greater experience of working with people with a learning disability would have significantly higher levels of knowledge. Fourthly, scores on LDKQ immediately after training would be higher than pre-training scores. Finally, levels of knowledge as assessed by LDKQ would be retained over time.

4.2 Internal Consistency

In relation to hypothesis 1, the LDKQ demonstrated a moderate level of internal consistency (Alpha 0.54). A number of items showed small negative item-total correlation scores (Range -.03 – -.14) suggesting that these items (questions 5, 8, 9, 11 and 26), did not correlate well with overall total scores. Subjects' total scores were not related to correct scores on these individual items, which contributed to the low internal consistency value. The item-total correlations of all items could be regarded as low with highest being .39 (question 1). This suggests that each individual item did not strongly relate to total scores on the LDKQ suggesting that

the items are problematic in some way. It may indicate that knowledge levels are not consistent in subjects within the sample or the items have been coded incorrectly or that subjects' misinterpreted the items. Even if subjects' score highly overall on the LDKQ, the results suggest that responses on individual items do not follow in the expected pattern i.e. a high total score would relate to a correct score on an individual item. If the LDKQ were highly internally consistent, there would be high item-total correlations suggesting consistency in subject responses and understanding.

4.3 Sensitivity to Levels of Knowledge

The LDKQ was found to be sensitive in its measurement of knowledge of the different areas relating to a learning disability as represented by each item. Item difficulty was calculated from the proportion (percentage) of subjects scoring correctly on an item and ranged from 22% (a 'difficult' question) to 92% (an 'easy' question). The average value for item difficulty was .57 and 8 items cluster around this value with a range of .55 – .64 (Q4, Q8, Q17, Q20, Q21, Q23, Q26 and Q30). The LDKQ also appears to be sensitive to measuring differences in total levels of knowledge in a sample of social care staff with scores ranging from 6 –25 (median score 17). There was no significant difference between male and female subjects in this sample.

4.4 Test-Retest Reliability

The LDKQ was found to be unstable in its measurement of knowledge over time with a correlation of $r = 0.102$. This suggests that total scores on the LDKQ do vary over time and may suggest that subjects' were 'guessing' in response to some items or that the items had been incorrectly coded. Alternatively, subjects' may have misinterpreted some of the questions and answered incorrectly leading to a lower correlation coefficient. An analysis of the reliability of subject responses over time revealed that certain items were responded to in an unreliable way by a considerable proportion of the sample (over 25%), perhaps suggesting poverty of knowledge. Interestingly, all but one of these items contained the words 'not' or 'cannot' and two thirds of the items were double negatives. This may mean that there is an association between the reliability of responses over time and subjects' uncertainty about the wording and meaning of the question.

Items answered incorrectly on both occasions, perhaps indicating misconceptions included those relating to diagnostic criteria, (Q1) '*...significantly low intelligence*', (Q2) '*...support with everyday living*' and diagnosis, (Q11) '*autism..*', (Q18) '*all people have a learning disability..*'. Items relating to terminology, (Q17) '*mental retardation and learning disability are the same thing*' and specific health difficulties (Q7) '*sexual problems...*' (Q12), '*eyesight..*' and (Q16) '*hearing difficulties...*' also fell into this response category. Those items reflecting uncertainty and unreliability of response over time and therefore perhaps 'guessing' included diagnostic criteria, (Q3) '*...acquired during childhood*' and diagnosis, (Q9) '*a learning disability and*

learning difficulty are not the same thing', (Q10) *'a learning disability is not a type of mental illness'* and (Q15) *'dyslexia is a type of learning disability'*. Also included were items relating to aetiology, (Q4) *'a learning disability cannot be inherited'* and health, (Q20) *'behaviour problems...'*, (Q24) *'health problems...'*, (Q30) *'mobility problems...'*.

4.5 General Population Sample

In relation to hypothesis 2, there was a significant difference between total scores on the LDKQ of social care staff with experience of working with people with a learning disability and a general population sample with no experience. The social care sample obtained higher total scores than the general population sample with the median total score for the social care sample at 17 (range 6-25) versus 15 (range 12 –20) for the general population sample.

There were a number of items on which a higher proportion of the general population sample scored correctly than in the social care sample. The biggest discrepancy between the groups was found on a question relating to the rights of people with a learning disability, where 97% of the general population scored correctly compared to 64% of the social care group. There were 9 questions in total that were scored correctly by a higher proportion of the general population group relating to diagnosis, aetiology, the law and service provision.

4.6 Years of Experience of Working in Learning Disability

Support was found for hypothesis 3, as there was a significant positive association between years of experience in working with people with a learning disability in social care staff and total scores on the LDKQ. This suggests that the greater the experience in working with people with a learning disability, the more knowledge is acquired of relevant aspects of this client group, as assessed by the LDKQ.

4.7 The Impact of Training on Knowledge Levels over Time

Hypothesis 4 was supported as a significant effect over time was shown between scores pre-training, immediately after and at one month after training. On further investigation, a significant difference was found between total scores on LDKQ pre-training and immediately after training.

There was no significant difference between total scores immediately after and at one month after training. This suggests that subjects' total score on the LDKQ post training remained stable after a period of one month. Subject knowledge when assessed immediately after the training session was similar to that found when assessed again at a later date suggesting that scores did not fall or increase in this time.

4.8 Properties of the LDKQ

The results obtained regarding the reliability of the LDKQ as a tool for measuring knowledge appear to fall short of the accepted criteria for a reliable and valid test as suggested by Guilford (1956) and Nunnally (1978). They suggest that a prerequisite of high validity for a scale is high internal consistency as this indicates that the test items are measuring the same variable and as such 'measuring what it is supposed to measure' (Kline, 1993). When tests have low internal consistency, the items are likely measuring a variety of variables and validity is called into question. Cattell offers an opposing view of internal consistency (Cattell & Kline, 1977) and argues that often if all the items are highly correlated, the test will be so narrow and specific that it will not be valid. The items will effectively be paraphrases of each other, measuring the same variable but not offering a breadth of information.

Given these two views, Kline (1993) cautions that high internal consistency is necessary but not sufficient for good tests. The LDKQ has a low to moderate internal consistency (Alpha coefficient 0.54) but on closer examination, the nature of the questionnaire implies that a high value may not be required. The LDKQ is not a measure of attitude or ability as is the case for intelligence tests. These types of tests clearly need to be internally consistent as they measure a specific attribute that should be in itself consistent i.e. a test that measures attitudes needs items that relate to a specific attitude and are homogeneous. The LDKQ does measure knowledge of a learning disability but each item reflects a diverse selection of facts and issues about this topic. The questions are not paraphrases of each other and the moderate

internal consistency suggests that items do measure a similar variable but there is a weak association with some items on the questionnaire.

Usually, if a low internal consistency value is obtained, items with low item-total values may be considered for deletion. The reliability is then recalculated in order to increase the homogeneity of the test. This would not be desirable for the LDKQ as each item provides an important insight into the specific areas of poor knowledge prevalent in the sample population. The level of internal consistency achieved may be seen as adequate for the purpose it would be used for. The questions are not paraphrases of each other and the moderate level internal consistency suggests that items do measure a similar variable but there is a weak association with some items on the questionnaire. The item-total correlations enable the identification of items that subjects do not appear to be answered by respondents in a way that would be consistent with their overall score and may reflect an area of poor knowledge.

One factor, which may have had an impact on the pattern of subject responding, was the wording of some of the questions as highlighted in the evaluation completed by subjects in the training sample. Some subjects commented that they found the negatively worded items e.g. *'a learning disability is not acquired during childhood'*, difficult to read and consequently incorrect answers may not reflect a poverty of knowledge but simply a misunderstanding of the question. The finding that items answered unreliably over time by the test-retest group all contained the words 'not' or 'cannot' and two thirds required a negative 'False' response may support this observation. Subjects did not answer in a consistent way over time to

items that could be viewed as being more demanding on the reader and could be open to errors in responding. It is not possible to state whether it is just coincidence that these negative items were answered in a way that could not clearly indicate a belief in a correct or incorrect response over time or whether it is due to misinterpretation of the question by the reader.

4.8.1 Validity

Measuring the validity of tests or assessment tools is reportedly a difficult task as it does not consist of a single statistical figure (Kline, 1993) therefore very few tests have good evidence of validity. Validity represents a collection of findings relating to whether a test measures what it is supposed to measure. The validity of the LDKQ is supported by virtue of each item being related to information found in the literature. There is evidence in the literature that individuals working with people with a learning disability need to be aware of all the areas covered by items in the questionnaire. There is also evidence that knowledge is poor in some areas e.g. knowledge of the diagnostic criteria of a learning disability and staff would benefit from training (McKenzie et al., 1999b).

Additionally, content validity of LDKQ was sought by consulting professionals in the field about the inclusion of items. Face validity or acceptability of the LDKQ to the chosen sample group was investigated through the evaluation sheet (Appendix 4) completed by the training group. Face validity is important for the motivation of subjects to complete the questionnaire as accurately as possible and is essential for

valid testing (Kline, 1993). The comments made by subjects indicate that they believed the items to be relevant to their job and provided answers to things they were not aware of. The confusion over the wording of items could be seen as a threat to face validity as it may affect subjects' motivation to continue making an effort to read the questions. The questionnaire was relatively short and took approximately 10 minutes to complete, further adding to the acceptability to subjects.

In general the results suggest that the LDKQ is a valid tool for assessing levels of knowledge of a learning disability in social care staff. It is sensitive to measuring differing levels of knowledge and is acceptable to the population it was designed. It has demonstrated moderate to low internal consistency and has been shown to be unstable in its measurement over time. The low values for reliability may be attributed to subjects 'guessing' answers to questions either because of poverty of knowledge or perhaps misinterpretation of the question.

4.9 LDKQ – Sensitivity to Levels of Knowledge

An analysis of question ease was calculated which suggests that the LDKQ is sensitive to differing levels of knowledge within the social care staff sample, as indicated by the range of values obtained. The values obtained indicating the proportion of subjects scoring items correctly can be converted to a percentage representing the proportion of the sample answering correctly. The items that the social care staff group found more 'difficult' can be divided into categories relating to health and diagnostic issues. Both of these categories are highlighted in the literature as areas where further training is required to inform staff of the

characteristics of the people with which they work and of the higher prevalence of health needs (McKenzie et al., 1999b; Espie & Brown, 1998).

Items that the group found 'easy' and were answered correctly by a large proportion of the sample included items relating to the prevalence of communication difficulties, head injury as a cause of a learning disability and a learning disability being a type of mental illness. It may be that communication problems are a more overt feature of many people with a learning disability than hearing problems for example. Participants may therefore be more aware of communication problems as being higher than in the general population. The item answered correctly by the highest proportion of subjects (92%) related to whether people with a learning disability could get married. This may reflect the underlying philosophy of social care environments based on the principle of normalisation and social role valorisation (Wolfensberger, 1972, 1983) that people with a learning disability should lead as 'ordinary' a life as possible. Marriage can be seen as a socially acceptable and indeed a desired goal in many individuals' lives and represents an aspect of what constitutes an ordinary life. It may be that enabling individuals with a learning disability to access the same opportunities as any other member of the population is a desired goal for social care staff within the 'normalised' social model of care (Espie & Brown, 1998). However it is equally important to recognise the inherent limitations of this client group in order to provide adequate support and in turn recognise duty of care.

Five items were answered correctly by approximately half of the sample, which may suggest that participants were generally unsure and randomly guessed the answer. Alternatively, it may be that these items relate to information that is known by half the social care staff group but not by the majority. This may perhaps depend on the individual characteristics of the people that they work with e.g. if the person has epilepsy or mobility problems but may not generalised to the population of people with a learning disability.

4.9.1 Knowledge of Diagnostic Criteria

Approximately three-quarters of subjects answered one of the items relating to the diagnosis of a learning disability (Q1 '*...significantly low intelligence*') incorrectly. This result concurs with previous studies that have found that knowledge of the diagnostic criteria of a learning disability is low in residential care staff (McKenzie et al., 1999a, 1999b). When compared with the fact that a high proportion of subjects correctly answered the item regarding marriage (92%), it could provide evidence to support the claim that they do not have a clear understanding of their duty of care. If they did, they would be aware of the cognitive limitations inherent in a learning disability and the implications of this on individuals' capacity to consent to the act of marriage.

Three items associated with the diagnostic criteria of a learning disability as stated in DSM IV (American Psychiatric Association, 1994) were answered unreliably or incorrectly over time. Subjects demonstrated a lack of clear understanding that a

learning disability is acquired during childhood with only a quarter of subjects responding correctly on two separate occasions. This concurs with previous studies (McKenzie et al., 1999a, 1999b) finding this to be the least identified criterion in samples of social care staff. Subjects appeared unsure whether autism and dyslexia were types of learning disability with 91% and 74% scoring either incorrectly or inconsistently to each respectively over time. This perhaps further indicates their confusion about what constitutes a learning disability.

A recent study investigating the awareness of autism in social care settings (Murray et al., 1999) revealed that residential and day service staff had had a relatively poor awareness of the features and needs of people with autism. In this sample only 4% of day service staff and 0% of residential staff were able to identify the four areas by which autism is defined. The present findings add support to the suggestion that social care staff are unclear how autism and learning disability are associated.

4.9.2 Knowledge of Health Issues

Subjects found items relating to the prevalence of hearing loss (Yeates, 1992; Kerr et al., 1996), eyesight difficulties (Kerr et al., 1996; McCulloch et al., 1996) and sexual problems in people with a learning disability (Kempton & Kahn, 1991; McCarthy, 1996; McCarthy & Thomson, 1997) 'difficult' to answer. This was reflected by the low percentage of subjects scoring correctly (26%, 27% and 22% respectively). This may again indicate a belief that people with a learning disability are the same as

everyone else, including health and physical issues (Espie & Brown, 1998). If this is the case then subjects may be ignorant of the impact that a learning disability has on a person's physical and brain development. The increased prevalence of sensory difficulties may not be evident to direct care workers, as it may be more difficult to assess or identify changes within this population. Hearing and eyesight difficulties may appear to be less common precisely because of the lack of knowledge and awareness on the part of caregivers and the difficulty people have in communicating their problems (Kinell, 1987).

A lack of awareness of the global and developmental nature of a learning disability may have contributed to incorrect answers relating to sexual problems. Historically, people with a learning disability were considered to be asexual (Niederbuhl & Morris, 1993; Brown, 1997) and it may be that this belief is still prevalent. Sexual issues relating to people with a learning disability may not be addressed by the organisations involved in this study and it may be that there are no policies and procedures for informing untrained staff in this area (Kempton & Kahn, 1991). Consequently subjects appeared to be unaware of the prevalence of sexual difficulties and needs.

The area of sexual problems in this client group could include the prevalence of sexual abuse (Turk & Brown, 1993; McCarthy, 1996), and the lack of sexual knowledge, social conventions and appropriateness of behaviour (Collins & Cozens, 1999). There are also issues relating to the restriction of opportunities for developing relationships which may encompass, staff attitudes (Murray et al., 1999), poor

finance, poor mobility and an individual's self esteem (Collins & Cozens, 1999).

Subjects generally appeared unaware of the potential difficulties relating to clients in their care, which may have an influence on their ability to support a client in this area.

Four items relating to problems identified as being of increased prevalence by the Health of the Nation Strategy for people with learning disability (DoH, 1995) namely, health, behaviour, and mobility problems were answered either incorrectly or unreliably over time by 70%, 79% and 61% of the sample respectively. This perhaps lends credence to the existence of the myth that people with a learning disability are in good health and may imply an avoidance of 'labelling' people with a learning disability (Espie & Brown, 1998). This apparent lack of awareness of some aspects of health needs supports Espie and Brown's (1998) claim that carers are poorly trained to identify such needs and enable individuals to access health services. If direct carer workers are not alert to potential difficulties associated with a learning disability, they may be less likely to notice changes or attribute changes to a health need as oppose to an aspect of personality for example.

4.9.3 Knowledge of Aetiological Factors

Items that appeared 'easy' to answer by the total sample with a high percentage scoring correctly included questions on aetiological factors, (Q19) '*a head injury...*' (83%), and (Q5) '*a virus..*' (74%). Other items included those on diagnostic issues (Q10) '*...is not a type of mental illness*' (83%), (Q28) '*...can be diagnosed with a*

brain scan' (74%) and health issues, (Q25) '*communication problems...*' (83%).

Although these questions were answered correctly by a large proportion of the sample (over 70%), other questions which could be related to them may not have been answered correctly. There is a discrepancy between subject knowledge within broad parameters such as health. It seems that subjects may respond correctly as a group to one question on health e.g. communication (83% correct) but a larger proportion of subjects may respond incorrectly to other questions pertaining to health e.g. nutritional problems (29% correct). This suggests that the sample as a whole has good knowledge in some areas relating to a learning disability but is clearly lacking knowledge in other areas. This comment has to be tempered by an acknowledgement that subjects' understanding of the question as mentioned earlier may have influenced their responses.

Subjects demonstrated a lack of clear understanding of some of the aetiological factors associated with learning disability. It may be that they do not need to understand the causes of a learning disability, however the variety of causes can have potentially important implications for everyday functioning. For example, Fragile-X is an X-linked chromosomal abnormality carried by mothers and passed on to their offspring. It is thought to be the most common inherited cause of a learning disability affecting both males and females (Hatton, 1998). However, only about a third of females and not all males has significant intellectual impairment (Hagerman & Cronister, 1991). There are recognised features of Fragile-X, e.g. hyperactivity, which is most obvious in males and has consequences for the support such individuals should receive.

4.10 The Association between Item 'difficulty' and Reliability of Response

The items that subjects in the total social care staff sample found 'difficult' to answer by virtue of the fact that a lower proportion of subjects answered them correctly (less than 30%), were associated with reliable responses in the test-retest group but indicated a belief in an incorrect answer. Over 70% of subjects per item answered wrongly. The items were answered incorrectly on both occasions suggesting that subjects held misconceptions about the items rather than being uncertain about their replies. This applied to question 1 '*...significantly low intelligence*', question 7 '*sexual problems...*', question 12 '*eyesight problems...*' and question 16 '*hearing problems...*'. This perhaps suggests that in these cases the wording of items may be secondary to actual levels of knowledge in influencing responses of subjects.

Those questions answered correctly by a significant proportion of the total sample (over 60%) were also those which were answered reliably over time by the test-retest group, perhaps indicating a belief in a correct answer. It indicates that this sample of social care staff clearly do have some stable knowledge of a learning disability but that this knowledge is perhaps not as integrated and broad as it could be. For instance, levels of knowledge of health issues are not consistent and understanding of the defining features of a learning disability is not integrated.

4.11 Experience and Knowledge Levels

The finding that individuals with more years of experience of working in learning disability were associated with higher levels of knowledge as measured by the LDKQ supports findings in the literature. Increased contact with this client group has been found to result in higher levels of knowledge of the criteria of a learning disability, specific interventions and more positive attitudes (Bromley & Emerson, 1995; Hames, 1996; McKenzie et al., 1999a).

The comparison with a general population sample allowed for the scores of the social care sample to be put in the context of individuals assumed to have very little experience of people with a learning disability. The range of scores in the general population sample is relatively small (12-20) and clusters around the median (15) perhaps suggesting an element of chance or guessing in the answers. A comparison of the range of total scores for each group showed that some people in the social care group significantly less than (range 6-25) the lowest score obtained in the general population. It is not possible to attribute concrete reasons why this may have happened but it suggests that there are some people working with this client group that do not even have a basic understanding of the relevant features and issues relating to a learning disability. A basic understanding may be taken as a total score within the range of scores obtained in the general population (12-20). This finding is consistent with previous findings that direct care staff demonstrate low levels of knowledge about the clients they work with (McKenzie et al., 1999a).

Although care was taken to ensure a random sample of the general population was included, there may be biases within this small sample group in terms of social or educational background. Such biases may result in an unrepresentative sample of baseline knowledge levels and inflated total scores. An alternative explanation is that knowledge of a learning disability in social care staff becomes ‘institutionalised’ in that the principle of normalisation and ‘ordinary living’ becomes distorted. Despite such biases, a significant difference was found between total scores in the two samples. The median scores of 17 (range 6-25) for social care staff and 15 (range 12 –20) for the general population indicate that social care staff generally have higher levels of knowledge of a learning disability as proposed in hypothesis 2.

4.12 The Impact of Training

The results indicate that levels of knowledge increase immediately after the completion of a training session focused on providing accurate information pertaining to each item. The subjects initially completed the LDKQ ‘blind’ and were then guided through the answers to each question with opportunities for discussion and further explanation of the literature relating to the correct response. Subjects marked their own responses correct or incorrect and when all 30 questions had been explained, they were required to complete the LDKQ again but with the benefit of newly acquired information. It must be acknowledged that the scores at this point in time may not reflect a true integration and acquisition of knowledge by subjects but may simply reflect a test of memory recall. The immediate completion of the LDKQ after being given the correct responses may have meant that subjects simply

remembered the response required. There is a question whether subjects would have had sufficient time to process the information given and make sense of it in relation to their pre-existing knowledge.

4.13 Factors Affecting the Acquisition of Knowledge

There were a number of factors present in the training session that may have facilitated the recall of information from memory and lend support to this assertion. Models of memory hypothesise that a number of factors work to facilitate the recall of information from memory including, *organisation* (Mandler, 1967), the presence of *cues* that have been encoded with the to-be-remembered information or that are present on retrieval (Tulving, 1974) and *elaborative rehearsal* (Craig & Watkins, 1973). There was a combination of these factors within the training session.

It was *organised* by the very structure of the questionnaire as subjects were clearly guided through the format of the LDKQ. The questionnaire itself was used to provide the format and structure of the training session, guiding subjects through the questions and answers. *Cues for retrieval* were given during the first administration of the questionnaire as subjects linked the question with their response. The questions were repeated in a visual format in the LDKQ question and information manual (Appendix, 3). At this point the question was associated with the correct answer. The question and correct response may have been encoded and associated together. During the second administration of the LDKQ, the questions and format

of the LDKQ acted as retrieval cues and prompts. Subjects may have been able to access the question and correct response together.

Elaborative rehearsal of the information was encouraged by subjects marking their own responses and by the discussion of each item. As well as the 'True or False' answer, a brief explanation of the background to the item was provided and subjects were prompted to turn to the appropriate appendices, which contained more detailed material. It is known that people generally recall the 'gist' or meaning of an experience rather than specific words or phrases (Baddeley, 1966) therefore this process was aimed at making the material meaningful by increasing the associations within memory (Craik & Watkins, 1973).

The results suggest that these factors did indeed combine to contribute to increased levels of scores on the LDKQ. This provides evidence that the format and presentation of the session was appropriate and achieved the desired result in most cases. The format was essentially didactic in nature but also included elements of a 'lesson' (Buckley & Caple, 1995) by the inclusion of questions and answers. This format was flexible and although it was as structured and standardised as it could be for the purposes of the study, it did allow for digressions depending on the interests and points made by each group.

Discussion was included to reinforce key points but judging by the comments received on the evaluation, some subjects would have preferred more time for this. However, if subjects are unwilling to participate in discussion then it is difficult to

make it a focus of the session as it a two way process and is not productive if subjects opt out (Buckley & Caple, 1995). One training session took place at the end of a working day before the staff meeting and in hindsight it may have been better to schedule it for a time when subjects were not fatigued and perhaps less motivated to engage in discussion. Motivation is a key feature in learning (Bandura, 1977) and is related to a person's ability to pay attention to material and make it available for encoding in long term memory. This may be a factor in the long-term retention of information.

4.14 The Retention of Knowledge over Yime

Previous studies have found the format of training described above to be effective in increasing verbal knowledge but having little impact on behaviour, therapeutic competence or generalisation of skills (Ziarnick & Bernstein, 1982; Smith et al., 1992; Jahr, 1998). This may well be the case for training sessions intended to impart certain skills or procedures. This was not the aim of the present study, which intended to provide a theoretically based background from which other skills and information could be developed. The importance of a theoretical background in training has been emphasised (Koegel et al., 1978) as has the topic of 'ground work' (Binney, 1992) in beginning to prepare staff for more specific information on management techniques and interventions.

Despite the caution in interpreting total scores immediately after training as an indication of increases in knowledge levels, it seems that subjects may have

integrated the information in to their existing knowledge to a degree, as shown by the scores achieved at one-month after training. Total scores remained at a significantly higher level than pre-training scores. However, as discussed earlier, a closer analysis of the reliability of subject responses on individual items revealed that a proportion of subjects continued to respond in a way that suggests they had not fully integrate the new knowledge in to their existing knowledge. Alternatively some subjects scored correctly when assessed one month after training when they had scored incorrectly immediately after training. This may suggest that time is required to alter responses and may support the notion that assessment immediately after training does not measure integration of knowledge.

4.15 The Influence of Pre-existing Beliefs

The schematic theory of memory and knowledge (Schank & Abelson, 1977; Cohen, 1993) can be used to infer why this may have occurred. This theory suggests that incoming information is influenced by pre-existing knowledge in the form of schemas. Schemas aid the interpretation of experiences and situations and on recall, inferences are made about what should have happened and what makes sense in terms of pre-existing knowledge. The forgetting or distortion of information on recall occurs when elements of the experience do not fit with the schemas. The memory is adapted and changed so that it 'makes more sense' (Cohen, 1993).

In terms of recall of the answers to the LDKQ, the fact that subjects answered unreliably to some questions perhaps indicates that the beliefs and knowledge they

held prior to training remain unchanged. A description of 'beliefs' would refer to the fact that they are thought of as consisting of non-evaluative knowledge about the world, such as the needs and abilities or causes of learning disability, rather than judgements. Whereas, values are concerned with '*an individual's sense of what is desirable, good, valuable and worthwhile*' (Gross, 1992) and therefore contain a judgement regarding the importance of beliefs held. Beliefs and values combine to form attitudes, and are thought to exert an influence over an individual's behaviour. Attitudes serve a number of important functions that enable people to adapt and respond to what is happening in around them (Baron & Byrne 1991). Functions of attitudes have been described by Hayes (1994) and include; a knowledge function, an adjustive function, a value expressive function, an ego defensive function, an object appraisal, social adjustment and social identification function and externalisation. It may be that the beliefs and attitudes held by subjects prior to training served to influence their responses after training.

In the time between the training session and follow up, information may have become forgotten and distorted under the influence of these beliefs. This may provide further evidence that this form of training fails to alter underlying belief systems, which have a strong influence over the behaviour of people in daily life and interactions with others. This comment is true for approximately one third of the sample, on specific items. A number of these items were negatively worded which may have been a persistent problem in responding correctly e.g. '*a head injury cannot cause a learning disability*' or '*a virus cannot cause a learning disability*'.

4.16 Knowledge Levels following Training

4.16.1 *Diagnostic Criteria*

Between 29% and 42% of subjects scored unreliably on items relating to diagnosis e.g. (Q28) *'a learning disability can be diagnosed by a brain scan'*, (Q3) *'a learning disability is not acquired during childhood'*, (Q11) *'autism is not a type of learning disability'*, (Q15) *'dyslexia is a type of learning disability'* and (Q10) *'a learning disability is a type of mental illness'*. Despite being given clear and concise information, with further information to refer to in their own time, some subjects continued to be uncertain about what constitutes a learning disability. The vast majority of subjects continued to score correctly on items relating to the other criteria of a learning disability, namely (Q1) *'...significantly low intelligence'* (92% correct) and (Q2) *'...support with everyday living'* (100% correct). These items had previously had very low correct response rates (22% and 56% respectively) and are arguably the most relevant to direct work with this client group. They underlie the concept of duty of care and highlight the fact that people with a learning disability have measurable and specific difficulties in some areas of daily living that require the support of others.

4.16.2 *Service Provision*

The fact that the item, (Q6) *'most people with a learning disability live in residential care'* was answered unreliably over time and correctly by a lower proportion of

subjects one-month after training (67%) than immediately after training (88%), may indicate a bias in the perceptions of some subjects. They may view all people with a learning disability as requiring the level of support they provide within their service. Everyday they work with people with a moderate to severe learning disability and fail to appreciate that there is a larger proportion of people with a mild learning disability who require a minimum of support and manage relatively independently (DoH/SSI, 1992). It seems this belief was maintained over time.

4.16.3 Behaviour Problems

Comments were made during one session that the prevalence of behaviour problems in this client group was dependent on the service providers' ability to support and manage an individual. Careful analysis of behavioural difficulties, appropriate support and functional communication training for instance, can often ameliorate the incidence of some difficult behaviour (Carr & Durand, 1984; Emerson, 1995, 1998). However, the very nature of a learning disability and its association with impairments in brain functioning suggests that people with a learning disability have more difficulty in coping with the demands of day to day life, socialisation and learning from past experience (Collins & Cozens, 1999), than the general population. This is partly the reason why behaviour difficulties are more common, despite the attempts by services to provide support. Even though initially subjects appeared sceptical of this point (47% scoring correctly), over time they appear to have integrated this new knowledge. Although scores were unreliable over time, a higher

proportion of subjects scored correctly at one-month follow up (79% scored correctly).

4.16.4 Health Issues

On questions relating to health issues e.g. (Q24) '*health problems...*' and (Q30) '*mobility problems...*', a higher proportion of subjects scored correctly at one-month after training (83% and 88% respectively) than immediately after training (59% and 72% respectively). This perhaps indicates that time is required for the consolidation of knowledge to occur. Despite suspecting that scores immediately after training could be attributed to memory recall, it appears that given time memory can become more efficient. The information is perhaps made meaningful by subjects as they reflect on the material by using the information manual and through discussions with colleagues. They may also begin to think about the clients they work with and how the information may apply to the people they work with day to day.

Some items relating to health were answered at a consistently similar level on both occasions after training e.g. (Q7) '*sexual problems...*' (97% and 92%), (Q12) '*eyesight problems...*' (94% and 96%), (Q21) '*epilepsy...*' (94% and 100%), (Q25) '*communication problems...*' (100% and 100%) and (Q29) '*nutritional problems...*' (97% and 96%). Subjects appeared to have taken on board the notion that people with a learning disability are not as good health as the general population and have difficulties in specific areas (Espie & Brown, 1998; HMSO, 1996).

Some participants commented during the session that question 8, '*the law is the same....*' was slightly ambiguous. While it is true that general law is the same for this client group as for the general population, the question was intended to highlight the important differences and how they apply to people with a learning disability. There was an increase in correct scores at one month after training from 56% to 67% which may suggest that participants had accepted this interpretation of the item however the increase is small and participants may continue to find the question ambiguous.

The results obtained from subjects at one-month after training suggests that levels of knowledge as measured by the LDKQ are retained over time. There was a slight decrease in correct scores at one month after training on 20 questions (mean decrease 10.65%, Range 1-30%) when compared with scores immediately after training. However, scores do not fall back to pre-training knowledge levels. This statement was true for all items except question 27 '*there are more women than men with a learning disability*'. The proportion of participants scoring correctly on this item fell to below pre-training levels at one month after training, from 81% to 71%. There is no clear reason for this but the missing participants at one month after training may have influenced this pattern of response.

4.17 Participant Evaluation

The comments received by participants after completing the training session (n=28) were generally positive and suggested that they found it a valuable and useful experience. The lower median and modal score of 3 (Ok) for the length of the session reported by 44% of the group may relate to the time of day it was held at with participants becoming fatigued when the session was at the end of a working day. The lower ranges of scores of 2 (Poor) for clarity and length of the LDKQ reported by 30% of the group and by 4% of the group relating to format of the questionnaire suggest that some participants found it difficult to understand and perhaps found it too long. A score of 2 (Poor) was obtained for the length, value of information and structure of the session but on closer analysis this was reported by only 4% of the group for value and structure of the session and 8% for length. This suggests that some participants did not find the exercise useful but the modal values obtained for each aspect above suggest that these lower scores were not representative of the entire sample and only related to a small proportion of the sample. The highest modal rating obtained of 5 (Good) was given by 60% of the sample to the question pertaining to relevance of the questions to working with people with a learning disability. This provides evidence that the questions are relevant to the population in question and lends weight to the argument for retaining all items in the questionnaire.

Given that lower ratings were given for certain aspects of the LDKQ and training session, it may be that aspects of both could be improved. Some suggestions

provided by participants included altering the wording of the questionnaire and altering the format of the answers i.e. 'agree or disagree' as oppose to 'True or False'. The timing of the training session appeared to be important and where possible arranging a time when participants are not weary from working should be considered. One participant would have liked more information before the session. A letter was sent to organisations briefly outlining the session but providing too much detailed information may have acted as a bias, allowing participants the opportunity to talk about it and perhaps read relevant literature. This would not have given a true reflection of knowledge levels, as they would not be completing the LDKQ 'cold'.

Additional comments received from participants highlighted that they found it useful to have the time to review the facts about learning disability. They often do not have time to consider such a broad perspective because of the pressure of working with clients. This emphasises the importance of regular, relatively short reviews or training sessions to enable staff to maintain the levels of knowledge they already have but also to keep abreast of new developments in understanding. It can be easy for organisations to become complacent about updating information and current practice as they concentrate on the day to day functioning of their service.

It seems that participants appreciated the time to refresh their understanding of the clients with which they work and have a reference booklet in the form of the information manual, to refer back to at a later date. There were comments that appeared to suggest that some participants were not fully aware of the broad effect

that having a learning disability can have on a person's life, development and interaction with others. The informal feedback given by participants was generally that they had enjoyed the session and found it informative.

4.18 Methodological Difficulties

There are a number of methodological difficulties within this study that may have had an impact on the reliability of the LDKQ and need to be considered when interpreting the results or replicating the study.

A number of methodological flaws were identified from comments made by participants mainly relating to the wording of the items. This ranged from disliking the negative questions to reporting that the 'back to front' format was useful in focusing the reader's attention to the meaning of the question and consequently making the reader work harder to respond in the appropriate way. This may be an argument for keeping the 'not' words and the double negative style of questions however there is also the issue of attempting to tap into levels of knowledge with the least amount of error from other sources.

Although an attempt was made to ensure the questions were at a level most people could understand by calculating a reading ease score (Flesch, 1948) based on word and sentence length, this did not account for level of grammatical difficulty. Elland and Rogers (1993) recommend that questionnaires should contain 40-60% 'true' items and 'not' words should be omitted. It may have been more effective to follow

these guidelines and reword some items to reduce the response error and measure levels of knowledge more clearly. The LDKQ does contain 50% 'true' items but a third of these items contain the word 'not'. More problematic perhaps are some of the 'false' questions that are effectively double negatives, containing 'not' and answered 'false', which account for nearly half.

If the LDKQ were to be used in the future, the educational level of the sample being studied would need to be taken in to account and an judgement made as to whether the current questions were at a grammatical level that could easily be understood by most subjects. It may be that the current study could be replicated using an adapted version of the LDKQ, without the complication of negatives words and the difference in scores could be compared.

Suggested changes to the format and wording of the items have been discussed and it may be prudent to reword some items to reduce the errors in response that could be attributed to misunderstanding of the question rather than lack of true knowledge. This would give a clearer picture of levels of knowledge. An additional suggestion by one of the subjects was to alter the response labels from 'True or False' to 'Agree or Disagree'. It was thought that this made more sense in terms of asking about an individual's interpretation of the items. This may make the items appear more subjective when in fact the items are objectively 'True or False'.

Another option would be to add an 'Unsure' set of categories which would allow subjects to clearly state if they did not possess the necessary knowledge to answer

the question with certainty. This would more accurately reflect individuals specific training needs. Any significant changes to the questionnaire would require a replication of this study to establish internal consistency and reliability over time. This may be a very useful process and would result in a refinement of the tool, which is only possible after this initial investigation and pilot with a target population.

Another issue that arose from the evaluation was that some subjects felt that they already had a good understanding of the facts about a learning disability and clearly from the total scores of the sample, some people did score highly. This begs the question of appropriateness of the training for different levels of experience in a staff group. If subjects felt that they already knew the information, this may affect their motivation to complete and participate in the session.

This issue can be linked to Vygotsky's (1978) level of proximal development. His theory applied to children and focused on the collaborative nature of development whereby adults or more experienced peers provide a 'scaffolding' or context for a child to start to build competency and work independently. If applied to the training setting, this principle implies that staff training should be pitched at a level and in a way that can be understood by its participants. Indeed studies indicate that training should be aimed at a level which subjects can relate to and will find useful in their work Sperlinger (1989). This is something to consider but it must be acknowledged that the majority of subjects did not generally hold this view.

A further criticism was levelled at the presentation of the information session. Participants commented that more discussion and interaction would have been useful. To address this issue, the format of the presentation may be altered to incorporate an overhead projector presentation, using Power Point to present the information. This format may prove to be more interesting for participants and allow the presenter to show the question first and discuss the group's answers before showing the answer. Further discussion may take place after the answer and brief explanation is given. Another advantage to this format is the presentation may be paced according to each group and the attention of the group is focused on the question being addressed, which prevents the tendency for participants to read ahead in the information manual while an earlier question is discussed. This alternative format may provide more interaction and may have an impact on the efficacy of the training session.

Difficulties associated with the reliability of subject responses also need to be discussed. Some questions were answered unreliably in the test-retest sample, as discussed and total scores were found to vary over time in this sample. Kline (1993) identified a number of areas of distortion that may boost or distort reliability over time, which must be considered. The time period between administrations was only 2 weeks and it may be that subjects remembered their responses from the first occasion. They may have spoken to colleagues about the answers, which may have influenced their responses on time 2, resulting in unreliable responses over time. It is unlikely that these factors would have had a significant impact on total scores but may have contributed to the patterns of responses found on individual items.

Kline (1993) highlights the issue of sample size and its relation with standard error. A larger sample size would produce smaller standard errors resulting in a more robust and trustworthy analysis of reliability over time. Unfortunately time constraints meant that it was not possible to access the recommended 100 subjects (Kline, 1993) this part of the study.

Factors that may have had a negative influence on reliability over time include physical attributes of the subjects (e.g. fatigue at the end of the day). It is precisely these human qualities that mean that even the best test-retest score is never unity (Kline, 1993). The 'True or False' format left little room for error in terms of understanding test instructions but did leave the LDKQ susceptible to random answering or guessing as discussed above. Including a 'Don't know' column may be a way of avoiding this but the literature suggests that subjects have a response bias towards replies indicating 'Don't know' (Elland & Rogers, 1993; Jarvie et al., 1993). Including a 'Don't know or Unsure' category may however be more useful for identifying training needs and may reduce the errors in response that could occur due to misinterpretation of the question. This may be a useful alteration for the LDKQ if it is to be used within a training setting.

4.19 Implications for Practice

Possible uses of the LDKQ have been considered and firstly, it would appear to be a useful tool for measuring baseline knowledge and training needs within a group of

social care staff. The LDKQ could be effectively used for identifying specific areas where understanding or knowledge is lacking in order to target training. Secondly, it could be used as an introduction to the relevant facts and concepts relating to a learning disability for staff with little experience of this client group. The training session may be used as an induction session, using the LDKQ to assess changes in knowledge and the session itself to discuss the issues in more depth. A recent Scottish Office Review (2000) recommended that carers should have access to training and advice to help support them in looking after a person with a learning disability. The LDKQ and information manual would provide a clear, concise and accessible format for disseminating information about people with a learning disability.

The LDKQ was only used with respect to social care staff in this study but it may be relevant for use with a number of different professions e.g. for induction training with new nurses, trainee clinical psychologists or GP's. For each group a reliability analysis would need to be undertaken. The LDKQ may not discriminate sufficiently between different levels of knowledge for some of these groups but this evidence could then be used to alter the questions in relation to each discipline and develop a specific questionnaire for each profession.

It was not within the scope of this study to assess whether knowledge levels are related to more practical everyday aspects of social care workers interactions with their clients. It would be an interesting avenue for future research to examine whether levels of knowledge as assessed by the LDKQ correspond to the

management of daily situations. This could be assessed using vignettes of situations relating to each area covered on the questionnaire. After categorising qualitative comments in to appropriateness of response, this could be compared with the score obtained on the questionnaire. This is not ideal and the best approach would be to observe the interactions of subjects and clients.

An alternative approach that would not assess the association between knowledge and management but which would make the material more meaningful to subjects would be to present the training in the given format and afterwards to encourage subjects to think about their own clients. Within the bounds of confidentiality, instances where an aspect of the training was relevant could be discussed. This approach is in line with the concept of *psychological fidelity* (Baldwin & Ford, 1988) whereby to increase the effectiveness of training, the material presented should have a similar meaning to situations and experiences found within the workplace.

4.20 Conclusion

In conclusion, the reliability and validity studies completed in the development of the LDKQ provide some evidence for the practical applicability of the tool in social care settings and it's ability to assess knowledge. The LDKQ has a moderate level of internal consistency but is unstable in its measurement of knowledge over time. The low levels of test-retest reliability obtained may be attributed either to subjects 'guessing' on items because of a lack of clear knowledge regarding the issue in question or perhaps a misinterpretation of the question caused by confusion over the

wording. Both of these explanations may result in response errors, which would reduce reliability over time and would have an impact on internal consistency, as items would not correlate well with total scores. This ambiguity precludes a clear conclusion being made over the reliability of the LDKQ in measuring levels of knowledge of a learning disability. However, the results indicate that the LDKQ is sensitive in measuring different levels of knowledge on some topics. The omission of items in an attempt to increase consistency is not desired as each item provides important information about specific areas of knowledge and to omit any one would reduce the discriminative power of the questionnaire.

The LDKQ and accompanying training session have proved effective in increasing awareness of the facts and issues related to a learning disability within social care settings. The process of training was acceptable to participants, in terms of accessibility, level of difficulty, amount of information and length of session. The provision of a manual that was concise, easily understood and could be retained and kept for future reference was popular by participants.

It is suggested that by increasing the awareness of the basic issues included in the LDKQ, subsequent training focussing on more specific topics such as challenging behaviour, autism or duty of care can be placed in the context provided by pre-existing knowledge. It may be that the integration of new information will be easier and the information will 'make sense' to individuals in terms of the client group with which they work. This may be an area that could be investigated in the future.

This initial investigation into the applicability and reliability of the LDKQ and training session has provided key information about areas in which the questionnaire could be refined to increase reliability e.g. the addition of an 'Unsure' category and rewording of some questions to reduce response error. Issues have also been raised about the format of the training sessions and suggestions made as to how changes could increase subject participation and make the material meaningful to participants.

Further work in this area will continue with the aim of providing an easily accessible, valid and reliable tool for imparting basic information about aspects of a learning disability to those people involved in working with this client group. This may help to fulfil the legal obligation of direct care workers that,

'Persons professing skills in working with the handicapped... should be aware of the characteristics and susceptibilities of the categories of handicap with which they work'.

(Ward 1984, pp. 57).

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LEARNING DISABILITY KNOWLEDGE QUESTIONNAIRE **(LDKQ)**

Please answer TRUE or FALSE to ALL of the following questions

	TRUE	FALSE
1. People with a learning disability have significantly low intelligence.		
2. People with a learning disability need help with everyday living.		
3. A learning disability is not acquired during childhood.		
4. A learning disability cannot be inherited.		
5. A learning disability cannot be cured.		
6. Most people with a learning disability live in residential care.		
7. Sexual problems are more common in people with a learning disability.		
8. A learning disability is not a type of mental illness.		
9. A learning disability and a learning difficulty are not the same thing.		
10. The law for people with a learning disability is the same as for everyone.		
11. Autism is not a type of learning disability.		
12. Eyesight problems are more common in people with a learning disability.		
13. A virus cannot cause a learning disability.		
14. Hyperactivity is a type of learning disability.		
15. Dyslexia is a type of learning disability.		
16. Hearing problems are more common in people with a learning disability.		
17. Mental retardation and learning disability are not the same thing.		
18. All people have a learning disability to some degree.		
19. A head injury cannot cause a learning disability.		
20. Behaviour problems are not more common in people with a learning disability.		
21. Epilepsy is more common in people with a learning disability.		
22. People with a learning disability can get married.		
23. Health problems are not more common in people with a learning disability.		

24. Communication problems are more common in people with a learning disability.
25. People with a learning disability have the same rights as the general population.
26. There are more women than men with a learning disability.
27. A learning disability can be diagnosed with a brain scan.
28. Nutritional problems are more common in people with a learning disability.
29. Mobility problems are not more common in people with a learning disability.
30. A learning disability is not infectious.
31. People with a learning disability cannot learn new skills.
32. People with a learning disability cannot have children.
33. People with a learning disability always have disruptive behaviour.
34. Some people with a learning disability find it hard to show their feelings in appropriate ways.
35. People with a learning disability do not grieve.
36. People with a learning disability can have the same type of psychiatric disorders as the general population.
37. It is against the law for people with a learning disability to have sex.
38. It is not against the law for people with a learning disability to drive a car.
39. People with a learning disability are more at risk of developing emotional disorders.

LEARNING DISABILITY KNOWLEDGE QUESTIONNAIRE

(LDKQ)

Male / Female (please circle)

Experience in learning disability (in years) _____

Age _____

Please answer TRUE or FALSE to ALL of the following questions.

	TRUE	FALSE
1. People with a learning disability have significantly low intelligence.		
2. People with a learning disability need support with everyday living.		
3. A learning disability is not acquired during childhood.		
4. A learning disability cannot be inherited.		
5. A virus cannot cause a learning disability.		
6. Most people with a learning disability live in residential care.		
7. Sexual problems are more common in people with a learning disability.		
8. The law for people with a learning disability is the same as for everyone.		
9. A learning disability and a learning difficulty are not the same thing.		
10. A learning disability is not a type of mental illness.		
11. Autism is not a type of learning disability.		
12. Eyesight problems are more common in people with a learning disability.		
13. A learning disability cannot be cured.		
14. Hyperactivity is a type of learning disability.		
15. Dyslexia is a type of learning disability.		
16. Hearing problems are more common in people with a learning disability.		
17. Mental retardation and learning disability are not the same thing.		
18. All people have a learning disability to some degree.		
19. A head injury cannot cause a learning disability.		
20. Behaviour problems are not more common in people with a learning disability.		
21. Epilepsy is more common in people with a learning disability.		
22. People with a learning disability can get married.		

23. It is not against the law for people with a learning disability to drive a car.
24. Health problems are not more common in people with a learning disability.
25. Communication problems are more common in people with a learning disability.
26. People with a learning disability have the same rights as the general population.
27. There are more women than men with a learning disability.
28. A learning disability can be diagnosed with a brain scan.
29. Nutritional problems are more common in people with a learning disability.
30. Mobility problems are not more common in people with a learning disability.

TRUE	FALSE

Thank you for your time and co-operation.

LEARNING DISABILITY KNOWLEDGE QUESTIONNAIRE

(LDKQ)

1. *People with a learning disability have significantly low intelligence.*

TRUE

- ☐ General intellectual functioning is defined by the intelligence quotient (IQ) obtained by assessment with one or more of the standardised individually administered IQ tests. Significantly sub-average intelligence functioning is defined as an IQ of 70 or below. This results in a reduced ability to learn new skills and understand new information.
- ☐ (Appendix 1, section 1.2)

2. *People with a learning disability need support with everyday living.*

TRUE

- ☐ This means that people with a learning disability need help with at least two of the following skill areas; social/interpersonal skills, communication, self-care, home living, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.
- ☐ (Appendix 1, section 1.2).

3. *A learning disability is not acquired during childhood.*

FALSE

- ☐ A learning disability is acquired during childhood. The onset must be before the age of 18 and needs to have a lasting effect on development.
- ☐ (Appendix 1, section 1.2).

4. *A learning disability cannot be inherited.*

FALSE

- ☐ A learning disability can be inherited. Genetic factors can influence the very early development of the foetus. Genetic disorders and chromosomal disorders include the commonly known syndromes e.g. Down's syndrome, Tuberous Sclerosis, Fragile-X Syndrome and Prader-Willi.
- ☐ (Appendix 2, section 2.1.1).

5. *A virus cannot cause a learning disability.*

FALSE

- ☐ A virus can cause a learning disability. Prenatally viruses can affect the development of the foetus, for example cytomegalovirus, toxoplasmosis, syphilis and rubella virus. Infections such as meningitis and encephalitis at birth or during childhood can result in a learning disability.
- ☐ (Appendix 2).

6. *Most people with a learning disability live in residential care.*

FALSE

- ☐ A small proportion of people with a learning disability lives in residential care. They tend to be people with increased levels of disability and additional needs. Individuals with a mild learning disability tend to live on their own or with their family.
- ☐ In an area with a population of around 100, 000, approximately 300-400 out of an estimated prevalence of 2000 people with a learning disability may live in staffed accommodation.
- ☐ Approximately 12% of all people with a learning disability live in residential care.

7. *Sexual problems are more common in people with a learning disability.*

TRUE

- ☐ People with a learning disability are vulnerable to engage in inappropriate sexual behaviour e.g. public masturbation, exhibitionism, and inappropriate sexual advances towards children or less able adults.
- ☐ Such behaviour often forms part of the normal developmental process but individuals with a learning disability often experience a lack of privacy, little formal education on sex and personal relationships, limited opportunity to learn appropriate sexual behaviour, a denial of sexuality and restricted social networks. They may not learn the “socially acceptable” way to express their sexual feelings.
- ☐ Other factors that increase the risk of sexual problems include physical disability, medical problems, and history of sexual abuse, all of which are associated with having a learning disability.
- ☐ (Appendix 6)

8. *The law for people with a learning disability is the same as for everyone.*

FALSE

- ☐ General law, which applies to everyone, also relates to people with a learning disability.

However,

- ☐ Specific legislation refers to people with a learning disability and covers sexual abuse, exploitation, treatment of mental illness and conviction and disposal following criminal offences.
- ☐ (Appendix 5)

9. *A learning disability and a learning difficulty are not the same thing.*

TRUE

- ☐ The term “learning disability” is used in the UK and was previously known as “mental handicap”. Mental handicap is used in the International Classification System of DSM IV and ICD10 and requires three criteria to be present.
- ☐ (Appendix 1, section 1.2).
- ☐ “Learning difficulties” is an educational term. In learning difficulties the development in a specific area e.g. reading, expressive language is impaired but there is not a generalised impairment in intellectual development and adaptive functioning.
- ☐ (Appendix 1, section 1.3.1).

10. *A learning disability is not a type of mental illness.*

TRUE

- ☐ A learning disability is diagnosed on the basis of intellectual ability, adaptive functioning and onset prior to 18 years.
- ☐ A learning disability can be recognised by behavioural and psychological processes that are *below* what is expected.
- ☐ Mental illness can be recognised by the impaired *quality* of these behavioural and psychological processes.
- ☐ Each type of mental illness e.g. anxiety, depression requires a different set of criteria to be fulfilled.
- ☐ Adults with a learning disability can suffer from the same types of mental disorder as people with normal intellectual functioning.
- ☐ People with a learning disability have a prevalence of co-morbid mental illness that is about 3-4 times greater than the general population.
- ☐ (Appendix 3, section 3.3)

11. *Autism is not a type of learning disability.*

TRUE

- ☐ It is possible to have autism and have normal intellectual functioning therefore it is not a type of learning disability.
- ☐ Autism is a spectrum disorder, affecting people with varying degrees of intellectual ability and presenting with an array of complex behaviours.
- ☐ It is estimated that approximately 65-88% of autistic individuals is classified as having a learning disability.
- ☐ (Appendix 1, section 1.3.1)

12. *Eyesight problems are more common in people with a learning disability.*

TRUE

- ☐ The prevalence of visual disorders ranges from 28-80%, depending on the type of population surveyed.
- ☐ Vision becomes poorer with increasing level of intellectual disability.
- ☐ Common difficulties include, squint, cataracts, disorders of the optic nerve and refractive errors.
- ☐ The Health of the Nation Strategy for people with Learning Disability (DoH 1995) identified eyesight problems as one of a number of health problems, which are common in people with a learning disability.
- ☐ (Appendix 3, section 3.5)

13. *A learning disability cannot be cured.*

TRUE

- ☐ A learning disability is a significant, life long condition, which by definition cannot be cured.

But,

- ☐ A learning disability results from an interaction between a person's adaptive and intellectual functioning and so appropriate support and services can have a significant influence on this.
- ☐ During development, biological or environmental factors have damaged the brain, which results in difficulties in brain processing.
- ☐ Environmental changes can influence performance but only within the limits determined by underlying impairments.
- ☐ (Appendix 1)

14. *Hyperactivity is a type of learning disability.*

FALSE

- ☐ Hyperactivity is not a type of learning disability as a learning disability consists of three specific criteria, intellectual ability, adaptive functioning and onset prior to 18 years.
- ☐ Hyperactivity is a description of a type of behaviour e.g. restlessness, fidgety etc and while it may be more common in people with a learning disability, it is possible to be hyperactive and have normal intellectual and adaptive functioning.
- ☐ (Appendix 1)

15. *Dyslexia is a type of learning disability.*

FALSE

- ☐ Dyslexia is not a type of learning *disability* but can be classified as a learning *difficulty* and is diagnosed by difficulties in understanding and processing words and difficulties in writing.
- ☐ The development of reading and writing is impaired but there is not a generalised impairment in intellectual development and adaptive functioning.
- ☐ (Appendix 1, section 1.3.1)

16. *Hearing problems are more common in people with a learning disability.*

TRUE

- ☐ The prevalence of hearing loss in people with a learning disability is not clear but estimates range from 5-60% with average occurrence estimated at 25 %.
- ☐ The Health of the Nation Strategy for people with Learning Disabilities (DoH 1995) identified hearing problems as one of a number of health problems, which are common in people with a learning disability.
- ☐ (Appendix 3, section 3.7)

17. *Mental retardation and learning disability are not the same thing.*

FALSE

- ☐ Mental retardation and learning disability are the same thing.
- ☐ In the USA, mental retardation is the term used for what is known as “learning disability” in the UK.
- ☐ (Appendix 1, section 1.1)

18. *All people have a learning disability to some degree.*

FALSE

- ☐ To have a learning disability, the three criteria of significant impairments in intellectual and adaptive functioning and onset during childhood must be present.
- ☐ (Appendix 1)

19. *A head injury cannot cause a learning disability.*

FALSE

- ☐ If a head injury has a significant impact on the development of the brain and occurs before the age of 18 years, it can cause a learning disability.
- ☐ (Appendix 2, section 2.2)

20. *Behaviour problems are not more common in people with a learning disability.*

FALSE

- ☐ 15-20% of people with a learning disability presents significant and active challenges to those that live and work with them.
- ☐ Common types of problems include aggressive, self-injurious, sexually inappropriate, destructive or socially unacceptable behaviour e.g. faecal smearing.
- ☐ (Appendix 4)

21. *Epilepsy is more common in people with a learning disability.*

TRUE

- ☐ There is a strong relationship between severe brain impairments, severe learning disability and epilepsy.

Prevalence of epilepsy in people with a learning disability

■ Total prevalence	30%
■ Profound learning disability	50%
■ Mild learning disability	6%

Prevalence of epilepsy in the general population

■ Total	0.5-1%
■ Lifetime prevalence	2-5%
□ (Appendix 3, section 3.2.2)	

22. *People with a learning disability can get married.*

TRUE

- There is no law against people with a learning disability getting married however there are issues around a person's capacity to consent to and understand the marriage agreement.
- *'A persons capacity is judged on the basis of his or her ability to understand the information relating to the decision in question, to weigh that information and to make a voluntary choice.'* (Murphy and Clare, 1997)
- A person may be judged capable of making a decision in one set of circumstances but not in another and at one point in time, but at another.
- Where a dispute about capacity exists, the court will decide whether the individual has the capacity to make a particular decision.
- (Appendix 5, section 5.1 & 5.3)

23. *It is not against the law for people with a learning disability to drive a car.*

TRUE

- ☐ There is no law against people with a learning disability driving a car but as with anyone, all components of the driving test would need to be completed successfully.

24. *Health problems are not more common in people with a learning disability.*

FALSE

- ☐ People with a learning disability tend to have higher than average levels of health care needs.
- ☐ The Health of the Nation Strategy for people with Learning Disabilities (DoH 1995) identifies some health problems, which are common in people with a learning disability:

- | | | |
|--------------------------|-------------------------|---------------------|
| ■ Communication problems | ■ Hearing problems | ■ Eyesight problems |
| ■ Obesity | ■ Behavioural problems | ■ Epilepsy |
| ■ Psychiatric illness | ■ Respiratory disorders | ■ Mobility problems |

- ☐ Health problems may also be related to certain syndromes e.g. Down's Syndrome.
- ☐ (Appendix 3)

25. *Communication problems are more common in people with a learning disability.*

TRUE

- ☐ The prevalence of communication difficulties is estimated at between 50% and 80% in people with a learning disability.
- ☐ (Appendix 3, section 3.1.1)

26. *People with a learning disability have the same rights as the general population.*

TRUE

- ☐ The General Assembly of the United Nations produced the Declaration on the Rights of Mentally Retarded Persons in 1971, which states that;

'The mentally retarded person has the same rights as other human beings, including the right to proper medical care, an inherent right to respect for their human dignity and the same civil rights as other human beings.

Disabled persons shall be able to avail themselves to qualified legal aid when such aid proves indispensable for the protection of their persons.'

- ☐ (Appendix 5, section 5.2)

27. *There are more women than men with a learning disability.*

FALSE

- ☐ There are more males with a mild learning disability than females (ratio approximately 1.6:1).
- ☐ Some figures show that for severe learning disability there is no difference between the sexes while others indicate that there is a higher prevalence in males.
- ☐ (Appendix 1, section 1.2)

28. *A learning disability can be diagnosed with a brain scan.*

FALSE

- ☐ A brain scan is able to detect structural changes in the brain, which may have contributed to the development of a learning disability but this is not necessary or sufficient for a diagnosis of learning disability.
- ☐ The diagnosis of a learning disability is based solely on three criteria i.e. intellectual ability, adaptive functioning and onset before age 18.
- ☐ (Appendix 1, section 1.2)

29. *Nutritional problems are more common in people with a learning disability.*

TRUE

- ☐ Nutritional problems are present in up to 30% of people with a learning disability.
- ☐ Obesity is a particular problem and is up to twice as prevalent among people with a learning disability, compared with the general population.
- ☐ (Appendix 3, section 3.6)

30. *Mobility problems are not more common in people with a learning disability.*

FALSE

- ☐ Motor impairments, including cerebral palsy are present in 20-30% of people with a learning disability.
- ☐ (Appendix 3, section 3.1)

APPENDIX 1

DIAGNOSIS

1.1 TERMS

- ☐ *Mental retardation* is used in the International Classification System of DSM IV (APA, 1994) and ICD10 and is a medical term.
- ☐ *Mental Handicap* is also a medical term and was used in the UK but has been replaced by “*learning disability*”.
- ☐ Other terms used include *mental impairment* as a legal term and *learning difficulties* as an educational term.

1.2 WHAT IS A LEARNING DISABILITY?

Approximately 2 % of the UK population will have a learning disability. A learning disability is a significant, life long condition and cannot be cured. There are three essential features:

A) Significantly sub-average general intellectual function.

General intellectual functioning is defined by the intelligence quotient (IQ) obtained by assessment with one or more of the standardised individually administered IQ tests. Significantly sub-average intelligence functioning is defined as an IQ of 70 or below. This results in a reduced ability to learn new skills and understand new information.

B) Significant limitations in adaptive functioning in at least two of the following skill areas:

Social/interpersonal skills, communication, self-care, home living, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.

C) The onset of learning disability must be before the age of 18.

A learning disability is acquired during childhood and has a lasting effect on development.

(DSM IV, APA, 1994)

- ☐ The prevalence of learning disability is 23-24 per 1000 (DoH, 1996).
- ☐ There are more males with a mild learning disability than females (Richardson & Koller, 1985; McLaren & Bryson, 1987; Fryers, 1993).
- ☐ It may be that males are more likely to be labelled as having a learning disability than females due to the different sex-role expectations for males and females.
- ☐ Genetic disorders that are X-chromosome linked may also account for the difference, as males are more susceptible to such disorders.

1.3 LEVELS OF LEARNING DISABILITY

Learning disability can be divided into categories according to intellectual (IQ) level, as assessed by IQ tests. The categories give an approximate guide to the person's level of general functioning.

☐ **Mild Learning Disability**

About 85% of people with a learning disability fall in to this group. People with this level of learning disability can usually achieve social and vocational skills adequate for minimal self-support but may require help or guidance especially when under unusual social or financial stress. With appropriate supports, people with a mild learning disability are usually able to live in the community either in supervised settings or independently.

☐ **Moderate Learning Disability**

Approximately 10% of people with a learning disability fall in to this group. People with moderate learning disability are able to communicate using words, gestures or signs and they are able to care for themselves with some supervision. People with a moderate leaning disability can usually take part in unskilled or semi-skilled work under supervision in sheltered workshops or in the general work place.

☐ **Severe Learning Disability**

Approximately 3-4 % of people with a learning disability falls in to this group. People with this level of learning disability able to acquire some skills, with the support of others and are able to communicate in a simple way. Individuals can take part in simple tasks and engage in some social activities in supervised settings.

☐ **Profound Learning Disability**

Approximately 1-2 % of people with a learning disability falls in to this group. Individuals require highly structured environments with constant supervision and an individualised relationship with a caregiver. Some individuals can take part in simple tasks in supervised settings.

(DSM IV, APA, 1994)

1.3.1 Learning disability does not include:

People with normal intellectual functioning (IQ more than 70) whom do not have difficulties with daily living. A diagnosis of a learning disability is made whenever the three diagnostic criteria are met but not when only the following are present,

- Educational disadvantage
- Brain injury in adulthood
- Progressive neurological conditions in adulthood
- Physical disability alone
- Long term mental illness alone
- Learning disorders and communication disorders: The development in a specific area e.g. reading, expressive language is impaired but there is not a generalised impairment in intellectual development and adaptive functioning.
- Pervasive Developmental Disorders (PDD) (DSM IV, APA 1994)
 - PDD consists of four main criteria: qualitative impairment in social interaction; qualitative impairment in communication; restricted and stereotyped patterns of behaviour, interests and activities; and onset prior to 3 years of age.
 - Learning disability often accompanies pervasive developmental disorders, 75-80 % of individuals have both.

APPENDIX 2

CAUSES

- A learning disability can be caused by genetic or environmental factors, alone or in combination. A learning disability can be inherited, as genetic factors influence the very early development of the foetus. Environmental factors act to influence the further development of the foetus, as well as during birth and in childhood (Bouras et al., 1999)

The following information was taken from Connor & Ferguson-Smith, 1993; Fryers & Russell, 1997; McLaren & Bryson, 1987; Plomin et al., 1997. In Emerson et al., 1998.

2.1 PRENATAL CAUSES

2.1.1 Genetic disorders

- Genetic disorders and chromosomal disorders include the commonly known syndromes.

Examples include:

	Estimated incidence
Down's syndrome	1:660-700 births
Prader-Willi syndrome	5-10: 100 000
Klinefelter syndrome	1:1000 live male births
Turner's syndrome	1: 4000 live female births
Tuberous Sclerosis	1: 3000

	Estimated incidence
Inborn errors of metabolism	
e.g. Phenylketonuria	1: 30 000 (60% have learning disability)
Lesch-Nyhan	1: 20 000 new-borns
Fragile X syndrome	1: 1100 – 2 500 male births
	1: 1 700 - 5 000 females
Neural tube defect	1:500 births

2.1.2 Environmental causes

Causes	Examples	Estimated incidence
Infections	Cytomegalovirus	0.4-2.2% all live births
	Toxoplasmosis	480 births / year in UK
	Rubella virus	Fewer since MMR vaccination
	Syphilis	
Physical / Nutrition	Irradiation, drugs, severe malnutrition, smoking, injury	
Maternal factors	Hypothyroidism	1: 4000 births
	Placental insufficiency	-
	Diabetes	-
	Toxaemia	-
	Foetal alcohol syndrome	20 –50% risk in alcoholic mother
Others	Cerebral palsy	1: 500 live births

2.2 BIRTH

2.2.1 A learning disability can be caused through difficulties during delivery.

Examples include:

- Prematurity ■ Birth injury ■ Asphyxia ■ Anoxia
- Infection at birth ■ Intra-uterine growth retardation

2.2.2 Immediate postnatal disorders.

Examples include:

- Hypoxia ■ Intraventricular haemorrhage ■ Rhesus incompatibility

2.3 FOLLOWING BIRTH

- ☐ This period includes infancy, childhood and adolescence, up to age 18 years.

Examples include:

2.3.1 Severe physical injury

- Abuse / non accidental injury ■ Accidents ■ Neurotoxins e.g. lead
- Post status epilepticus

2.3.2. Infections

- Meningitis ■ Encephalitis ■ Severe gastro-enteritis e.g. typhoid
- Brain abscess

2.3.3. Progressive neurological disease

- Sturge-Weber syndrome

2.3.4. Deprivation

- Maternal, sensory, cultural and environmental

APPENDIX 3

HEALTH NEEDS

3.1 HEALTH NEEDS OF PEOPLE WITH A LEARNING DISABILITY

People with a learning disability tend to have higher than average levels of health care need than the general population (Rodgers, 1994).

- The Health of the Nation Strategy for people with Learning Disabilities (DoH, 1995) identifies some health problems, which are common in people with a learning disability:

- | | | |
|--------------------------|-------------------------|----------------------|
| ■ Communication problems | ■ Hearing problems | ■ Eyesight problems |
| ■ Obesity | ■ Behavioural problems | ■ Epilepsy |
| ■ Psychiatric illness | ■ Respiratory disorders | ■ Mobility problems. |

3.1.1. Prevalence of health problems

Estimated prevalence

■ Communication difficulties	50-80%	(Mansell, 1993)
■ Visual and auditory defects	60%	(Vitiello & Behar, 1992))
■ Sub-optimal nutrition	30%	(Bond et al., 1997)
■ Behavioural and Emotional disorders	up to 50%	(Bouras & Drummond, 1992)
■ Epilepsy	20-50%	(Corbett, 1993)
■ Cerebral Palsy/ other Motor impairments	20-30%	(McLaren & Bryson, 1987)

- **“People with a learning disability are not in such good health as the general population”** (Espie & Brown, 1998).
- Health status data collected in 1995 show that,

‘People with learning disability scored lower on all attributes, (physical functioning, general health, emotional and mental health) apart from bodily pain (where they scored higher) and vitality (where they scored the same), as the general population’.

(Welsh Health Survey, 1995, pp. 65).

The ‘attributes’ included physical functioning, social functioning, general health, emotional state and mental health.

3.2 SPECIFIC DISORDERS

- Health problems in people with a learning disability are often associated with specific disorders. For example:

3.2.1 Down’s Syndrome

- Approximately 50% are born with heart defects (Hallidie-Smith, 1985). Symptoms of congenital heart disease include shortness of breath and lethargy.
- Approximately 30% of children develop obstructive sleep apnoea, a serious respiratory disorder affecting sleep and resulting in daytime sleepiness (Marcus et al., 1991).
- Approximately 80-90% has hearing loss in one or both ears (Cunningham & MacArthur, 1981).
- Hypothyroidism affects about 40% of adults (Moss & Turner, 1995). Annual thyroid checks are necessary. Symptoms include weight gain, lethargy or cognitive decline (often mistaken for dementia).

- ☐ Individuals are at a higher risk of developing Dementia of the Alzheimer's type (Zigman et al., 1995, 1997).
- ☐ Depression is also associated with Down's Syndrome and may present as loss of interest, appetite, sleep or weight disturbance.

3.2.2 Epilepsy

- ☐ There is a strong relationship between severe brain damage, severe learning disability and epilepsy (Bouras et al., 1999).

Prevalence of epilepsy in people with a learning disability

■ Total prevalence	30%
■ Profound learning disability	50%
■ Mild learning disability	6%

(Corbett, 1981; Coulter, 1993; Richardson et al., 1979; Sheperd & Hoskins, 1989).

Prevalence of epilepsy in the general population

■ Total	0.5-1%
■ Lifetime prevalence	2-5%

(Brown et al., 1993; Goodridge & Shorvon, 1983; Muir et al., 1996).

- ☐ The prevalence of anti-epileptic drugs is high in people with a learning disability.
- ☐ Research shows that 53% of children and adults with learning disability are receiving at least one anti-epileptic drugs (Hogg, 1992).

3.3 MENTAL HEALTH

- People with a learning disability are at risk of developing mental health disorders due to the complex interaction of biological, psychological, social and family factors.

3.3.1 Biological factors

- Brain damage ■ Sensory impairments ■ Syndromes

3.3.2 Psychological factors

- Low intelligence and cognitive impairment resulting in poor coping mechanisms

3.3.3 Personality development

- Restricted and disadvantaged lifestyle during childhood- lack of non-disabled peers, lack of opportunities for exercising choice, low expectations and over-protection.
- The difficulties in bonding of disabled children with their parents.
- Parental acceptance and the influence on later development of self-control/esteem.
- Experiences of failure, rejection, separation and bereavement.
- Difficulty in forming and maintaining relationships leads to an increase in emotional and behavioural problems (Collins & Cozens, 1999).

Information was taken from Mental Health in Mental Retardation: The ABC for Mental health, primary care and other professionals, (1999), by Bouras, Holt, Day and Dosen (Eds.).

3.3.4 Facts about mental health and learning disability

- ☐ Adults with a learning disability suffer from the same types of mental disorder as people with normal intellectual functioning.
- ☐ People with a learning disability have a prevalence of co-morbid mental illness that is about 3-4 times greater than the general population (HMSO, 1996).
- ☐ Prevalence rates are estimated at 10-14% (Kerr et al., 1996)
- ☐ Depression and anxiety are the most common disorders (HMSO, 1996).

3.4 DEPRESSION

- ☐ Depression is strongly associated with low levels of social support and poor social skills (Reiss, 1994).

3.4.1 How does it present?

Often the same as in the general population i.e.

- Sleep disturbance (early morning wakening)
- Significant weight loss, change in appetite.
- Social withdrawal.
- Changes in mood, tearfulness / irritation.
- Decrease in skills of daily living and self-care.
- Increase in existing maladaptive behaviours.
- Increase in negative self-statements.

(O'Hara & Sperlinger, 1997)

3.5 ANXIETY STATES

- Studies show that 10-30% of people with a learning disability has generalised anxiety states (Ollendick et al., 1993).
- Panic attacks, specific phobias, posttraumatic stress disorder and obsessive-compulsive disorders are also common.

3.5.1 How does it present?

- Physical symptoms; nervousness, sighing, palpitations, shortness of breath.
- Observed behaviour; ritualistic and repetitive behaviour.
- Low mood, sleep disturbance, withdrawal, self injury.
- Increase in pre-existing behaviour or somatic problems (headaches, mobility difficulties, vomiting).
- Statements about fear, discomfort or unease.

(O'Hara & Sperlinger, 1997)

3.6 DEMENTIA

- Dementia can be seen clinically in between 15-40% of adults with Down's syndrome over the age of 35 years (Prasher & Krishan, 1993). Pathological changes in the brain usually develop by the time the person is in the early 40's but clinical symptoms of dementia are not evident until later (Moss & Turner, 1995).

3.6.1 *How does it present?*

- ☐ Diagnosis is based on the presence of a number of cognitive impairments that interfere with social functioning.
- Memory: impaired thinking, judgement, personality change, and difficulty speaking or co-ordinating movements, apathy, loss of daily living and self help skills, gait disturbance (Prasher, 1995; Evenhuis, 1990; Holland et al., 1998).
- The ruling out of depression or other causes for the decline in functioning.
- A general deterioration from a higher level of functioning.

3.7 HEARING LOSS

- ☐ The prevalence of hearing loss in people with a learning disability is not clear and estimates range from 5-60% with average occurrence estimated at 25 % (Kerr et al., 1996).
- ☐ Hearing loss is more prevalent in older age groups (Cooke, 1988).
- ☐ Hearing loss often goes undetected (Ellis, 1986) and can lead to behavioural disturbance that can be mistaken as psychotic episodes.
- ☐ In a sample of 500 people, 39.4% were found to have hearing loss (Yeates, 1992).
- ☐ Objective tests are available for the identification of hearing loss and treatment can improve speech intelligibility.

3.8 VISUAL DISORDERS

- ☐ The prevalence of visual disorders ranges from 28-80%, depending on the type of population surveyed (McCulloch et al., 1996).
- ☐ There is a highly significant trend towards poorer vision with increasing level of intellectual disability (McCulloch et al., 1996).
- ☐ Common diagnoses include; squint, cataracts, disorders of the optic nerve and refractive errors.

3.9 COMMUNICATION

- ☐ Compared with the normal pattern of development, people with a learning disability experience distortion and delay in their acquisition of language (Rondal, 1996).
- ☐ Individuals may have difficulties in expressing themselves verbally and/or understanding spoken words but may be able to communicate in other ways.
- ☐ Manual signs or symbol based communication boards are often used to accompany speech as they are often easier to teach and signs and symbols can be clearly associated with actions and objects.
- ☐ Any communication system must be understood and reinforced by others to ensure that it continues to be used effectively.
- ☐ Early communicative ability is associated with later social development (Bailey et al., 1996) and communication difficulties are associated with the development of difficult to manage behaviours.

3.10 NUTRITION

- ☐ Obesity is up to twice as prevalent in people with a learning disability as in the general population (Turner & Moss, 1996; Welsh Office, 1996).
- ☐ People with a learning disability may have difficulty understanding dietary education.
- ☐ Obesity is a risk factor for cancer, respiratory and cardiovascular diseases and diabetes.
- ☐ The majority of people with a learning disability do not do moderate or vigorous exercise (Turner, 1996; Welsh Office 1996).
- ☐ Lack of exercise leads to a further increased risk of disease.
- ☐ Prescribed drugs (antiepileptic and antipsychotics) often have side effects, which include weight gain.

APPENDIX 4

BEHAVIOURAL DISORDERS

4.1 CHALLENGING BEHAVIOUR

'Severe challenging behaviour refers to behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be place in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of community services.'

(Emerson et al., 1987)

The term challenging behaviour has been used to describe high levels and combinations of aggressive, self-injurious, sexually inappropriate, destructive or socially unacceptable behaviour e.g. faecal smearing.

15-20% of people with a learning disability presents significant and active challenges to those that live and work with them (Keirnan & Qureshi, 1993).

- ☐ Challenging behaviours are more common in:
 - ☐ Boys and men.
 - ☐ People aged between 15 and 35 years.
 - ☐ People with severe learning difficulties.
 - ☐ People with specific syndromes e.g. autism.
 - ☐ People with sensory difficulties, specific difficulties with communication or mobility.

(Emerson, 1998)

4.1.1 Functions of behaviour

A number of different causes may contribute to the expression of challenging behaviour in an individual. Bouras et al. (1999) summarise the sources of possible causes into six categories:

- ☐ biological causes
- ☐ a response to a poor environment (low social interactions, a barren environment with few activities)
- ☐ a communicative act (expressing pain, anger, sadness or confusion)
- ☐ a response to mental trauma
- ☐ an association with mental illness
- ☐ a learned behaviour

Environmental consequences and contingencies can shape behaviour through positive and negative reinforcement, often through other people such as staff working with them (Emerson, 1998).

- 1) **Positive reinforcement** refers to an increase in the rate of behaviour, in response to the presentation of a positive event.
- 2) **Negative reinforcement** refers to an increase in the rate of behaviour, in response to the withdrawal of a negatively reinforcing event.

Behaviour may also be maintained by internal consequences e.g. clenching teeth to help pain. In this case behaviour is maintained by **automatic or perceptual reinforcement** (Lovaas et al., 1987; Vollmer, 1994). These may be positive or negative in nature (behaviour leads to positive internal state e.g. masturbation or a reduction in aversive stimuli e.g. clenching teeth.)

APPENDIX 5

THE LAW

5.1 MARRIAGE

- ☐ Any person who is of age and capable of understanding the nature of a consenting marriage is entitled to marry.
- ☐ All that is necessary is a broad understanding of the normal responsibilities involved in marriage.
- ☐ The European Convention on human Rights specifically enshrines the right to marry.
- ☐ If an objection is made to the Registrar General that one of the individuals is incapable of understanding the nature of the marriage ceremony, an assessment may be called for.

(McKay, 1997)

5.2 RIGHTS OF PEOPLE WITH A LEARNING DISABILITY

'The mentally retarded person has the same rights as other human beings, including the right to proper medical care, an inherent right to respect for their human dignity and the same civil rights as other human beings.

Disabled persons shall be able to avail themselves to qualified legal aid when such aid proves indispensable for the protection of their persons.'

(General Assembly of the United Nations, Declaration on the Rights of Mentally Retarded Persons, 1971)

- ☐ General law, which applies to everyone, also relates to people with a learning disability.

However,

- ☐ Specific legislation covers sexual abuse, exploitation, treatment of mental illness and conviction and disposal following criminal offences.

Difficulties with this client group because although they have the rights, they have difficulty expressing or exercising their rights or others not recognise their rights.

5.3 CONSENT

'A persons capacity is judged on the basis of his or her ability to understand the information relating to the decision in question, to weigh that information and to make a voluntary choice.'

(Murphy & Clare, 1997).

- ☐ A person may be judged capable of making a decision in one set of circumstances but not in another and at one point in time, but at another.
- ☐ Where a dispute about capacity exists, the court will decide whether the individual has the capacity to make a particular decision.
- ☐ Capacity to consent to treatment and consent to relationships are the most common dilemmas.

5.3.1 Consent to sexual relationships in women

Section 106 of the Mental Health (Scotland) Act 1984 states that:

‘It shall be an offence.....for a man to have unlawful sexual intercourse with a woman who issuffering from a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning.’

“Unlawful sexual intercourse” refers to sex outwith marriage.

“Arrested or incomplete development of mind” refers to a learning disability.

- ☐ Section 106 is designed to protect women with a learning disability from exploitation.
- ☐ Psychologists and medical practitioners may be needed to assess whether or not a person falls within the criteria for section 106.
- ☐ Assessment of “significant impairment” would be specifically around entering in to a sexual relationship and social functioning relevant to making a meaningful choice about a sexual relationship.

For example;

1. Does the woman understand about sexual relationships and their implications.
2. Does she have the ability to make informed choices?
3. Can she assert her will?

Section 106 may apply, however a relationship may not be viewed as exploitative (with people of a similar level of impairment). In this case, sex education may be appropriate as a way of enabling informed choice.

5.3.2 Consent to Sexual relationships in men

Section 13 of the Criminal Law (Consolidation) (Scotland) Act 1995 states that:

'A male person who is suffering from mental deficiency which is of such a nature or degree that he is incapable of living an independent life or guarding himself against serious exploitation cannot in law give any consent which.....would prevent a homosexual act from being an offence'.

A similar process of assessment would take place whereby answers to the following questions would be sought:

1. Does the man understand enough about homosexual relationships to make a meaningful decision to enter into one?
2. Was the man in a position to make and assert a real choice?

5.3.3 Consent to Medical Treatment

- ☐ No medical treatment can be given unless the patient has given an informed consent.
- ☐ Informed consent is not the same as passive acceptance.
- ☐ ***Informed consent involves having a basic understanding of the nature of the treatment, its purpose and the likely consequences.***
- ☐ Some people with a learning disability are able to give consent but others are not because they lack the necessary understanding.
- ☐ A doctor may decide to give treatment if it is in the best interest of a patient (in an emergency or if there is a severe risk to health) who cannot give consent.
- ☐ A parent or carer has no right in law to give consent on the behalf of an adult with a learning disability, without the approval of the court.

- A tutor dative can lawfully give consent for an adult with a learning disability. A tutor dative is a suitable person appointed by the court as a personal guardian of an adult with a learning disability with powers, which might include giving a valid medical consent.

5.3.4 Offenders with a learning disability

- The Scottish Home and health Department's circular "Interviewing of mentally Handicapped or Mentally Ill Persons", recommends that police should always try to interview people with a learning disability in the presence of an "appropriate adult", i.e. a relative, carer or someone with experience of people with a learning disability who is not a police officer.
- The role of the appropriate adult is to facilitate communication, not act as an advocate.

5.3.5 Consequences of a criminal act

- If a crime is a result of lack of social skills or training as oppose to "badness" then there may not be a prosecution. The person does not have the "mens rea" or guilty mind required to commit a crime.
- The procurator fiscal decides whether a prosecution will be in the public interest.
- If there is a conviction, a person with a learning disability may not be sent to prison. After considering medical evidence, a person may be detained in hospital or place under guardianship of the local authority.
- If a person has a severe learning disability, to the point that they would not be able at the time of the offence to understand what they did wrong, they are legally "insane". They would then be detained in hospital.

The information in Appendix 5 was taken from "Sex, Laws and Red Tape" (1991), by Colin McKay.

APPENDIX 6

SEXUALITY

6.1 *Sexual Issues*

- ☐ The United Nations in 1971 stated people's right to receive training in sociosexual behaviour, the right to knowledge and the right to express sexual impulses in the same forms that are socially acceptable.
- ☐ People with a learning disability are vulnerable to sexual exploitation partly because they do not usually receive credible or reliable sex education. They have few opportunities to make friends or learn appropriate sexual behaviour (Collins & Cozens, 1999).
- ☐ As a result, they are ill equipped to know when they are putting themselves at risk or have their problems recognised through routine health checks.
- ☐ People with a learning disability have lower levels of sexual knowledge and experience, more negative attitudes to sex and stronger sexual needs than people with physical disability, in all areas of sexuality (McCabe, 1999).

6.2 *Sexual Abuse*

- ☐ People with a learning disability are more at risk of sexual abuse than most other members of society (Bouras et al. 1999).
- ☐ The incidence of sexual abuse in people with a learning disability is estimated at 0.5 per 1000 (Turk & Brown, 1993).
- ☐ Adults of all ages and levels of disability are affected.

- ☐ The perpetrators are almost always male and are usually known or familiar to the person.
- ☐ The perpetrator often has a learning disability.
- ☐ People with a learning disability have a right to be protected from sexual abuse and exploitation.
- ☐ **All staff and carers should be aware that they have a duty to report an allegation of sexual abuse and this overrides their duty to keep a confidence.**

6.2.1 Effects of Sexual Abuse

- ☐ The effects of sexual abuse for people with a learning disability are assumed to be similar to the effects experienced by the general population but they may be expressed in a different way.
- ☐ The psychological effects of sexual abuse can be expressed as withdrawal, behaviour difficulties and emotional distress (Sobsey, 1994).
- ☐ Communication difficulties may effect the way in which emotional distress is expressed.

LEARNING DISABILITY KNOWLEDGE QUESTIONNAIRE (LDKQ)

EVALUATION

Thank you for taking part in this study. As part of the evaluation of the LDKQ and the information session, I would be grateful if you would complete the following questions.

Please circle the number that most accurately reflects your views.

Poor		Ok		Good
1	2	3	4	5

Learning Disability Knowledge Questionnaire

- 1. Clarity of the questionnaire.
- 2. Length.
- 3. Format.
- 4. Relevance of the questions to my job.

1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

Information session

- 1. Clarity of the session.
- 2. Length of the session.
- 3. Usefulness of the material to my job.
- 4. Value of the information.
- 5. Structure of the session.

1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

What did you find most useful?

Please turn over

Appendix 4